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IYUNIVESITHI YASEKAPA • UNIVERSITEIT VAN KAAPSTAD

DEPARTMENT OF SOCIAL DEVELOPMENT

WORKING IN PALLIATIVE CARE:
EXPLORING COMMUNITY NURSES' EXPERIENCES OF
THEIR WORK

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(WLLRAC004)

A Minor Dissertation submitted in partial fulfilment of the requirements for the
award of the degree of Masters of Social Sciences specialising in Clinical
Social Work Practice.

Faculty of Humanities

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I, Rachel Williams, do hereby declare that I empower the University of Cape Town to produce, for the purpose of research, either the whole or any portion of the contents of my dissertation entitled "Working in Palliative Care: exploring community nurses' experiences of their work," in any manner whatsoever.

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DEDICATION

This thesis is dedicated to my loving parents Deborah Williams and Vincent Williams, who have constantly made sacrifices to provide me with endless opportunities to pursue an education and academic career, while showing love and support every step of the way.

ABSTRACT

This study explored community-based Palliative Care nurses' experiences of their work. The aim of this study was to explore the positive aspects of working in palliative care, as well as the challenges that community-based nurses experience in their work. The coping strategies that are employed by these nurses to deal with the difficulties of their work were understood, and the participants provided recommendations to their organisations to improve their working experiences.

The research was conducted in two research settings, St Luke's Combined Hospices and Tygerberg Hospice, which are both non-profit organisations providing Palliative Care in the community. Permission was gained to conduct research by the St Luke's Combined Hospices Research Ethics Committee, and the Palliative Care Manager at Tygerberg Hospice. A qualitative research design was used to conduct this study, and purposive sampling was used to select the sample. Fourteen nurses were interviewed using a semi-structured interview schedule, and a digital recorder was used so that interviews could be recorded accurately. Qualitative data analysis was used to arrange the data into themes, categories and sub-categories.

Findings from the study indicate that there is a great sense of satisfaction from working in Palliative Care and positive aspects include feelings of honour and privilege, making a difference, appreciation from patients and families, life lessons learnt, having a role in the community and working in a team. The perceived challenges were emotional challenges such as persistent rumination about work, feelings of helplessness and dealing with challenging families. Organisational challenges pertained to demanding workloads and a lack of organisational support. Personal challenges were seen as having a negative impact on the physical health and family lives of participants. Lastly, environmental challenges included issues around safety and driving to communities. Coping strategies were the support from family and friends, avoidance coping and self-care as well as group support and debriefing and support from colleagues. Lastly, recommendations include an open-door policy within the organisation, improved training and education, a better understanding of community Palliative Care, improved interaction with staff and staff reward and recognition.

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CHAPTER ONE

PROBLEM FORMULATION

1.1 Introduction

This chapter provides the statement of the problem and the rationale and significance of the research. This will be followed by the research topic, questions and assumptions. Key terms will be clarified followed by the main ethical considerations. The personal stance of the researcher will be stated, an outline of the chapters will be presented, and a conclusion completes the chapter.

1.2 Statement of the problem

Cancer is defined as a term referring to the growth of abnormal cells in the body. These can affect any part of the body and spread to organs and each type requires different management strategies. Globally, Cancer is the second leading cause of death in the world, with an estimated 9.6 million deaths worldwide in 2018 (World Health Organisation [WHO], 2019a). The number of new cases in the next two decades are expected to rise by 70%, thus demonstrating the major impact of cancer on a global scale. The economic impact is great too, the global cost of cancer was approximately US\$ 1.16 trillion in 2010 (WHO, 2019a). In South Africa, approximately 100 000 people are diagnosed with cancer each year, and one out of four people are either diagnosed themselves or have family members, friends, or colleagues that have been diagnosed with cancer, with a survival rate of 60% (Cancer Association of South Africa [CANSAs], 2018).

Cancer management includes screening, early diagnosis, treatment and palliative care. Treatment includes chemotherapy, radiation, surgery and other medicines (WHO, 2019a). Historically, the focus in the medical field for cancer was prevention, treatment and cure, and the patients with advanced illness that could no longer benefit from curative treatment were often overlooked and were not offered further support (Clark, 2007:431). The great suffering of these patients was identified, and in response to this, Dame Cicely Saunders and colleagues opened the world's first hospice, St Christopher's Hospice, in London, which still exists today. The focus of these hospices was on cancer patients in the terminal phase with great suffering (Clark, 2007:431-433). Saunders introduced the notion of total pain in her writings, indicating

that she identified pain as a holistic burden on patients. The holistic burden refers to the fact that the impact of cancer is not only physical, that patients were experiencing social difficulties, emotional challenges and mental distress and patients would often express that all aspects of their lives were burdened (Clark, 2007:431).

Palliative care was the approach used within hospice settings primarily as Palliative Care uses a holistic approach when working with terminally ill patients, thereby responding to this notion of total pain as discussed above. However, over time, it was seen that this approach was used within other settings and was expanding, and up until today, palliative care is used in other settings as well. Palliative care is now, and will continue to be an upcoming approach to support the patient and their families in the end of life care (Clark, 2007:431-433). The alleviation of suffering is a main goal of palliative care yet suffering continues to be one of the biggest challenges experienced by 88% of patients with advanced cancer with 25% of these patients reporting unbearable suffering (Beng et al., 2017:869).

Palliative Care requires an interdisciplinary team approach which is crucial in providing holistic care and this consists of nurses, social workers, psychologists, physicians, physical therapists, occupational therapists, and carers, with the patient and their family at the centre (Paice, 2011:540-542; O'Connor, Fisher & Guilfoyle, 2006:134). The interdisciplinary approach requires team members to work closely together and to make joint decisions regarding intervention and care (Paice, 2011:540), however, the roles of each team member must be clearly defined to achieve optimal functioning (O'Connor, Fisher & Guilfoyle, 2006:134).

This study focussed on the experiences of nurses, who have a specific role and function within the Palliative Care team. Palliative care nurses are often the case managers who co-ordinate the team (Fakroodeen, Meiring & Stidworthy, 2017:2). In the two research settings where this study was conducted, nurses were case managers who were required to do the initial assessments and co-ordinate the care of the patient by referring to other team members. The main role of the professional nurse is to manage the physical wellbeing which includes managing medication, this includes pain and symptom control, wound management, establishing orientation and cognitive function, assessing the need for equipment to aid the patient, nutrition and hydration and managing habits that may affect the patient's comfort (Fakroodeen, Meiring & Stidworthy, 2017:6; Cherny, Fallon & Kaasa, 2015:364). Hospice

nurses in a study conducted described themselves as the link between home-based hospice services to the greater system (Ellington et al., 2018:215). However, in a study conducted with nurses providing palliative care, it was found that an equal amount of time was spent on psychosocial care of the patient and family (Weber & Grohmann, 2004 cited in O'Connor, Fisher & Guilfoyle, 2006:135), and nurses are often required to facilitate conversations about death and dying (Cheung et al., 2018:5). Since nurses have an increased involvement in patient care in comparison to other professionals, it has been found that they are likely to experience significantly more distress and anxiety (Cheung et al., 2018:5), as well as other emotional burdens which will be discussed later.

1.3 Geographical location of the problem

The research was conducted with community-based nurses within two organisations providing palliative care in the greater Cape Town area named St Luke's Combined Hospices and Tygerberg Hospice. Initially, it was intended that the research be conducted in St Luke's Combined Hospices only, however due to challenges with sampling, a decision was taken to expand the research into a second research setting.

St Luke's Combined Hospices is a registered non-profit organisation that was established in 1980 in response to a need for support for patients facing life-threatening illnesses and their families. A request by a 5th year medical student Christine Dare for Dame Cicely Saunders to visit Cape Town after working with her in England resulted in the establishment of the organisation (St Luke's Combined Hospices, 2018a). Their head office is in Kenilworth, Cape Town, but eight community hospice offices in various communities exist, to service the greater Cape Town area. At any given time, there are more than 500 patients who receive homecare and a maximum of 10 patients can be accommodated in the Inpatient Unit in Kenilworth. Staff and volunteers are used to provide the care service on behalf of the organisation, and great value is placed on these volunteers who play a big role in the service (St Luke's Combined Hospices, 2018a).

St Luke's care to patients and their families include, home care, in-ward care, emotional, psychosocial, spiritual care, and bereavement support. The purpose of home care is to care for patients and their families in the comfort of their own home, surrounded by the people that they love and within their own community, and the community hospices enable the teams to cater

to the specific needs of each community (St Luke's Combined Hospices, 2018a; St Luke's Combined Hospices, 2018b). Palliative care is provided by nurses at home and their task is to assess the needs of the patient and family, provide specialised nursing care and involve other members of the inter disciplinary team such as social workers, doctors, spiritual counsellors, and volunteers. The nursing service is available to patients and their families from 08h00 – 16h00 in the week, and telephonic support is available after hours (St Luke's Combined Hospices, 2018b). The researcher is an employee at St Luke's Combined Hospices, and the management of her dual-role will be discussed later.

Tygerberg Hospice is a registered non-profit organisation in Bellville, Cape Town, that has been operating since 1999 and started as a small team providing services to limited patients (Tygerberg Hospice, 2018a). Over the years, the organisation has expanded and is currently operating with three arms of the service, namely home-based care, intermediate care and palliative care. The home-based care service attempts to promote comfort with regards to care needs and minor ailments within the comfort of the individual's home. It is provided by trained community health workers working towards ensuring that patients experience a dignified death (Tygerberg Hospice, 2018b). The intermediate care unit is an inpatient facility that comprises of 40 beds and patients are admitted for reasons such as end of life care, rehabilitation, relief of suffering and promotion of comfort. Care is provided by a multidisciplinary team and the average length of stay is 14 – 42 days, and patients will be discharged home, or to another facility afterwards, if necessary (Tygerberg Hospice, 2018c).

The palliative care arm of the service at Tygerberg Hospice provides services to those with life-threatening illnesses. The care is provided at home by the inter-disciplinary team and addresses pain and other physical problems, as well as psychosocial and spiritual issues. Bereavement support is also provided when needed (Tygerberg Hospice, 2018d).

At the time of the study, the composition of the community nurses at St Luke's Combined Hospices was 20 in total, 18 permanent and two locum nurses. In terms of geographical areas, the communities covered a range of areas. A total of nine permanent nurses and one locum nurse from St Luke's Combined Hospices voluntarily participated in the study. At Tygerberg Hospice, there were five nurses working in the community, including the palliative care manager. The community covered by Tygerberg Hospice includes Northern Suburb

communities in Cape Town. A total of four of these nurses voluntarily participated in the study. Therefore, across both organisations, a total of 14 nurses participated in the study.

1.4 Rationale/significance

The prevalence of suffering amongst patients with advanced cancer indicates that nurses working with these patients have high rates of exposure to suffering. Palliative care professionals remain at risk for both burnout and/or compassion fatigue (Mota Vargas et al., 2016:169) because this level of exposure to suffering may lead to compassion fatigue (Booth, 1991 cited in Cherny, Fallon & Kaasa, 2015:252), which manifests as psychological, cognitive and interpersonal impairment (Cherny, Fallon & Kaasa 2015:252). A consequence of compassion fatigue is that professionals lose their ability to care for their patients (Joinson, 1992, cited by Yu, Jiang & Shen, 2016:30). There are potentially two negative outcomes of this, for the patient there may be further suffering, and for the nurse there may be an inability to meet organisational demands. Nurses in palliative care and hospice settings have reported that there is inadequate formal organisational support to help them cope with grief, sadness, hopelessness, guilt and the frustration that they often experience when caring for their patients (Funk, Peters & Roger, 2017:3; Beng et al., 2015:21; Rattner & Berzoff, 2016:248-249). This lack of support is compounded by a lack of training and education, large caseloads, understaffing and inadequate time to do their work.

The abovementioned places nurses in these settings at risk for developing burnout (Cherny, Fallon & Kaasa, 2015:162) which is the consequence of accumulated stressors due to the demands and responsibilities in the workplace (Yu, Jiang & Shen, 2016:30). Furthermore, burnout and compassion fatigue affect nurses beyond professional boundaries and it is seen that their personal relationships are negatively affected as well, ultimately decreasing their overall quality of life (Sanzo et al., 2015:201).

Although palliative care professionals are susceptible to these conditions, research has also revealed that those in palliative care and hospice settings have lower levels of burnout and/or compassion fatigue compared to professionals in other health care settings due to the satisfaction that they experience from their work (Sanzo et al., 2015:201). There are three main positive aspects highlighted in the literature which nurses have reported that lead to satisfaction. These are feelings of being special, whereby they feel that they are destined to

work with dying patients and that there are a select few that can do this, feelings of honour and privilege, which stem from their ability to be with patients during an intimate phase of their lives, and learning opportunities such as reflection on their own mortality, spirituality and faith, and finding meaning in life (White & Gilstrap, 2016:307-310). Furthermore, research has found that nurses in palliative care and hospice settings have employed their own coping strategies to deal with the challenges that they are confronted with. The common strategies used, as presented in the literature review, are the use of social support such as peer support from colleagues and friends outside of work, self-care through physical exercise, healthy eating, yoga, meditation and the use of humour, and emotional boundary setting, whereby they are mindful of not getting too close to patients emotionally (McConnell, Scott & Porter, 2016:915-916; Ablett & Jones, 2006:737). However, nurses feel that their organisations can do more to meet their needs, such as providing more training and education, formalised emotional support, opportunities for self-care and acknowledgement and reward (Al-Kindi, Zeinah & Hassan, 2014:471; Fitch, DasGupta & Ford, 2016:71; Whitebird et al., 2013:1537; Cherny, Fallon & Kaasa, 2015:248).

The purpose of this study was to better understand the positive aspects, as well as the challenges that Palliative Care nurses experience that could potentially detract from their work. This study also aimed to reveal the coping strategies employed by Palliative Care nurses to mitigate these conditions and provided them with an opportunity to express their needs and recommendations to assist them in coping effectively with their work demands.

Globally, the literature is consistent in identifying the experiences of hospice nurses as demonstrated in the literature review, and many of these experiences have been similar, however it was unclear whether the literature was applicable or relevant in the South African context as it is acknowledged that South Africa has a unique context, which is diverse in culture, religion, language and socio-economic status. The St Luke's Combined Hospices and Tygerberg Hospice communities are a microcosm of the South African context, whereby there is a diversity of patients with regards to culture, religion, language and socio-economic status who receive the service.

Crime Statistics SA (2015) has revealed that the prevalence of violent crimes in South African communities continues to be high, identifying Western Cape precincts such as Cape Town Central, Mitchells Plain, Nyanga and Kraaifontein in the top 10 areas with most reported

crimes. These communities are visited by some of the nurses that participated in this study. Arrive Alive (2018) specifically highlighted the issue of personal safety of paramedics that has increasingly been publicised in the media more recently. It has found that paramedics trying to provide emergency services are targets of criminal behaviour and their personal safety is placed at risk, with the extent of the risk including hijacking or death (Arrive Alive, 2018). With this, the issue of safety of other professionals in communities in Cape Town has also been highlighted in an article by Dano (2017) in Independent Online, indicating that attacks on teachers was extremely problematic. The media has demonstrated that providing services in dangerous communities puts the personal wellbeing of professionals at risk.

The findings of the study will be made available to all participants and their organisations, and it is intended that it will provide insight to community-based Palliative Care nurses' experiences of their work, and that the recommendations will be considered by these organisations to improve this, if needed.

1.5 Formulated research topic

Working in Palliative Care: exploring community nurses' experiences of their work.

1.6 Research questions

- What are the positive aspects that palliative care nurses experience in their work?
- What are the challenges that palliative care nurses experience in their work?
- What are the coping strategies that are used by these nurses to cope with their work?
- What recommendations would these nurses make to their organisation to improve their working experience?

1.7 Research objectives

- To explore the positive aspects that palliative care nurses experience in their work.
- To explore the challenges that palliative care nurses experience in their work.
- To understand the coping strategies that are used by these nurses to cope with their work.
- To ascertain the recommendations that nurses make to their organisation to improve their working experience.

1.8 Research assumptions

The researcher's assumptions were that nurses have challenging experiences in their work, and that these experiences impact on their ability to do their job effectively as they may lead to more serious conditions such as burnout and/or compassion fatigue. It was also assumed that there are positive experiences that the nurses experience, which lead them to continue to do their work. Further assumptions were that these nurses employ coping strategies in response to the demands of their work and that by exploring their coping strategies and existing support, informed decisions about support structures could be employed by the organisation to assist with the prevention of burnout and compassion fatigue. The final assumption was that these nurses had recommendations for their organisation to assist them in coping with their work more effectively.

1.9 Concept clarification

Patient

An individual who is receiving services from a medical professional (Liebeck & Pollard, 1994:588).

Nurse

A professional that is trained to care for sick or injured people (Liebeck & Pollard, 1994:553). In this study, nurse refers to Palliative Care nurses who provide care that promotes comfort and quality of life at the end of life.

Challenges

A situation or task that is difficult or demanding (Liebeck & Pollard, 1994:131).

Exploring

To examine or investigate something (Liebeck & Pollard, 1994:280).

Experiences

To observe, share in, or be affected by something personally (Liebeck & Pollard, 1994:279).

1.10 Ethical considerations

Some ethical considerations that were relevant and applicable to this study as discussed by Strydom (2011:115-126) and Creswell (2014) will now be discussed.

1.10.1 Avoidance of harm

It is the responsibility of the researcher to protect the participants from any harm, and in the social sciences, it is more likely that participants will experience emotional harm. Therefore, it is important for participants to be informed of the potential impact of the research and that should they wish to withdraw from the study at any point, they have the right to do so (Strydom, 2011:115). The participants in this study were informed of any potential effects of the study, and were reassured that should they experience any form of emotional harm, they could withdraw from the study at any point. After signing the consent form (see Appendix A), no participants withdrew from the study. Debriefing was also offered to all participants to manage any emotional harm that may have resulted in their participation in the study.

1.10.2 Informed consent

Participants should be informed as much as possible about what the research entails to be informed when they give consent to participate in the study (Strydom, 2011:117-118; Creswell, 2014). Participation in research should be voluntary and nobody should be forced to participate (Strydom, 2011:116-117). The participants in this research were reassured that their participation was voluntary and that they could withdraw at any point. They were also informed of the purpose and benefits, procedures, potential risks and discomforts, confidentiality and their rights in a letter requesting consent which was explained to them by the researcher. With this knowledge, they could make an informed decision when consenting to take part in the study. A consent form was clearly explained to each participant before the interview and was signed by each participant and the researcher (see Appendix A).

1.10.3 Deception of subjects and/or participants

The researcher should not deliberately or intentionally withhold information or misinform participants to gain consent that may not have been gained if this information was provided (Strydom, 2011:118-119). In this study, the researcher did not deliberately or intentionally deceive participants. The participants were clearly informed verbally and in writing about the purpose of the research, and no information was withheld. Participants were also informed by

the researcher that she was an employee at St Luke's Combined Hospices at the time of the study, but that her role in the study was that of a student researcher and not employee (see Appendix A, section 9).

1.10.4 Privacy, anonymity and confidentiality

Privacy, anonymity and confidentiality are synonymous and refer to the participants' right to decide how much information they would like to be revealed, while respecting and protecting their information and identity. Privacy of participants is to be respected and therefore it is the responsibility of the researcher to ensure that participants remain anonymous and their information be kept as confidential as possible (Strydom, 2011:119-121; Creswell, 2014). In this study, privacy was ensured by providing participants with the opportunity to decide where they wanted to be interviewed. Most participants were happy to be interviewed at their place of work, and only two were interviewed at their homes.

Anonymity and confidentiality was maintained and the researcher did this by only requesting information that participants were comfortable with, and by ensuring that information and findings could not be traced back to any of the participants by using pseudonyms in the interviews, transcriptions and findings. The researcher spent time with each participant, explaining confidentiality and how it would be maintained during and after the data collection process. A third party was used to transcribe the interviews, and she was asked to sign a confidentiality form (see Appendix B).

1.10.5 Actions and competence of the researcher

Ethically, researchers are required to ensure that they are adequate and equipped with the skills to conduct the study in all steps including data collection, data analysis and the writing of the findings (Strydom, 2011:123-124). The researcher had a supervisor overseeing this project and was confident in her interviewing and academic writing skills that she has developed as an undergraduate and postgraduate student and professional social worker.

1.10.6 Release or publication of findings

The release or publication of findings from a study should be presented in writing that is accurate, objective and not falsified (Strydom, 2011:126; Creswell, 2014). The data and findings of this study were compiled in a written report and should any of the participating

organisations request, the researcher will do an oral presentation of the findings. Participants received feedback via a written letter outlining the findings and recommendations that were identified in the study.

1.10.7 Debriefing of participants

Debriefing allows an opportunity for participants to reflect on the experiences had, the lessons learnt, and the impact of the study. This is a method to explore anything that may have been evoked during the study and process it to minimise emotional harm. It is also an opportunity for the researcher to rectify any misunderstandings that may have arisen (Strydom, 2011:122). After each interview, the researcher reminded each participant that debriefing was available if they felt that the interview evoked any difficult emotions. Debriefing was offered as optional to all participants and a registered social worker was available on standby to debrief participants. Her contact details were provided to participants for them to make direct contact if needed. The social worker that was available to offer debriefing was asked to maintain confidentiality and anonymity of who accessed her services but informed the researcher that none of the participants accessed her services within one month after data collection.

1.11 Reflexivity

According to de Vos et al. (2005:363), reflexivity refers to the researcher's personal perceptions and feelings in relation the research. The researcher, as a social worker at St Luke's Combined Hospices was passionate about the study and its findings as the researcher has worked in the field of palliative care, and has been faced with similar experiences as a professional. The researcher has found in her personal experience, that many people do not understand the positive and negative impact of working in Palliative Care and wanted to bring more awareness to this. Therefore, it was important for the researcher to be aware of and manage any personal feelings or subjectivity that was evoked from conducting this study. This was done by making use of supervision as much as possible and a willingness to be self-aware. The researcher was also mindful that her role with the participants was that of a researcher and not a social worker operating as an employee in the organisation. This was done by ensuring that her dual-role was closely monitored, the use of supervision and practising her role as the researcher in the pilot study, whereby she could reflect on any challenges pertaining to the dual-role and personal feelings about the study. These strategies assisted the researcher to manage appropriately and equipped the researcher to be consistently aware of researcher bias

and subjectivity throughout the process. Furthermore, upon completion of the study, the researcher views this research as valuable as she feels that the impact of working in the field of Palliative Care on professionals is significant and recognition of this is important in assisting professionals to cope with the demands of their work and express their needs to equip them to do so.

1.12 Outline of chapters

The following structure will be followed in this research report:

Chapter one presents the problem formulation and background, acknowledging the ethical considerations and the rationale of the study, and chapter two presents the literature review. The methodology used in the study will be discussed in chapter three, and chapter four discusses the findings. Lastly, chapter five presents the conclusions and recommendations based on the findings of the study.

1.13 Conclusion

This chapter has provided the context of the problem, the rationale for choosing to do this study, and the main research questions and assumptions, ethical considerations, reflexivity and clarification of key concepts. The following chapter discusses the literature pertaining to the study.

CHAPTER TWO

LITERATURE REVIEW

2.1 Introduction

This chapter discusses the existing literature relevant to the study. This includes the relevant legislation and policy, the theoretical frameworks underpinning the study, the positive and challenging experiences of palliative care professionals, and the coping strategies employed by professionals to cope with the demands of their work. The needs and recommendations of professionals working in this context will also be discussed.

2.2 Policy and legislation pertaining to the nurses providing palliative care

This section presents the policy and legislation that underpin and are relevant to the study. The chosen policy and legislation are highlighted as they speak to the working conditions in which nurses are expected to operate under.

2.2.1 The Occupational Health and Safety Act

The *Occupational Health and Safety Amendment Act, No. 181 of 1993* is legislation that regulates an employer's responsibility to prevent occupational injury and disease through the promotion of physical, psychological and emotional wellbeing of employees. The purpose of this act is to protect workers from any harmful or hazardous conditions that they may be exposed to through their work duties. The researcher believes community-based nurses are potentially more vulnerable than nurses in other settings such as hospitals and clinics, as they are visiting patients at their homes which may not be equipped with protocols and resources to protect them from health hazards. Furthermore, they also work in isolation, and are frequently exposed to death and dying, which may increase their risk for psychological and emotional harm.

The Act stipulates that employers must provide a safe working environment to employees that is not a risk to the overall health of their employees. It furthermore stipulates that employers should provide information and training pertaining to health and safety so that they may protect themselves, and ensure sufficient supervision to workers regarding their health and safety (*Occupational Health and Safety Amendment Act No. 181 of 1993*, 1993:8). This is particularly important for community-based nurses, as they work in environments which their employers

may have little or no control over, thus reinforcing the need for them to be equipped and empowered by their employers in ensuring their own health and safety.

This legislation is relevant to the study as occupational burnout and compassion fatigue have been found to compromise the well-being of employees and more specifically nurses in the field of palliative care. This Act indicates that it is the responsibility of the employer to ensure the wellbeing of its employees and this study intends to provide the organisations with guidelines to meet this responsibility through feedback from its employees.

2.2.2 The Rights of Nurses Policy

The South African Nursing Council (SANC) has drafted a policy which is named “The Rights of Nurses.” The purpose of this policy to promote nurses’ rights in terms of the Constitution of the Republic of South Africa and to ensure adequate service to patients and falls under the provisions of the *Nursing Act of 2005* (South African Nursing Council [SANC], 2017). The rights, as outlined in the policy, that is relevant to this study include the right to a safe working environment, proper in-service education relevant to the field of practice, continuing professional education, advocating for the protection of patients, refusing to work outside their scope of practice or unethical practice, and the right to a working environment that is not intimidating or threatening (SANC, 2017).

This policy is relevant to this study as it protects the rights and wellbeing of nurses and is therefore applicable to nurses working in palliative care environment that may be susceptible to a decrease in psychological, emotional and social wellbeing. Although this policy serves as a form of protection, when exploring nurses’ experiences of their work, it is also helpful to understand the rights of nurses as this may influence the expectations that nurses have of their work and/or employers. For example, when these expectations are unmet, or if they feel that their rights are not being promoted, the gap between their reality and expectations may be perceived as challenges in the work. Furthermore, their knowledge of their rights may influence the recommendations that they make to their organisations as they may perceive that it is their organisation’s responsibility to promote their rights. Therefore, this policy is relevant as if nurses are aware of their rights, the perceptions of their work may be informed by this, and this study aims to explore their perceptions of their work. The relevant theoretical frameworks will be discussed next.

2.3 Theoretical Frameworks

2.3.1 Systems Theory

Systems Theory in social work refers to social systems such as families, groups and communities, whereby they are connected through relationships with each other (Payne, 2014:184). The field of social work identified and began to adopt this model in the 1950s as it provided professionals with a holistic approach to understand how people function and are affected by their wider context as well as their inter-personal relationships (Walker, 2012:3-7).

In this theory, systems are divided into macro (larger), meso (medium) and micro (small) systems, which have sub-systems that are all interconnected (Walker, 2012:7; Payne, 2014:184). An example of this, when considering nurses, is that nurses as individuals belong to larger systems such as a families, churches, social groups, and geographical communities, and they contribute to, and play a role in these systems. Therefore, this theory views the individual person as part of larger systems, rather than isolated, and these systems are impacted when the individual is (Payne, 2014:185). The implication of this interconnectedness is that what happens in one system will inevitably affect the other connected systems, and this will be evident. For example, if a nurse is working overtime every day and giving a lot of her energy to her employment system, her role within another system, such as family may be affected as she may be exhausted and not be as present physically and emotionally to fulfil her role within her family system. Thus, a shift in relationships and roles within the entire family system to accommodate for her lack of energy would be required. This could extend to her role in other systems such as church and her community as well, thus demonstrating how her relationships may be impacted, but also how the other systems she forms part of need to shift to accommodate the demands that her employment system has on her. This is an example of a negative impact, however, the researcher also identifies that there may be positive shifts in nurses' other systems as well, depending on their experiences of their work, whereby if there is a positive experience at work, they can bring this positive energy back to their other systems such as families, churches and communities.

Systems theory is relevant to this study as it is important to acknowledge that the nurses in this study form part of greater systems such as their families, the organisation in which they work,

and their communities, and therefore their experiences of their work in palliative care extends to these systems.

2.3.2 Palliative Care

Historically, the term “palliation” derives from the Latin root word “palliare” which means to “cloak” or “conceal.” This has evolved into the concept of palliative care whereby the dying patient may not be cured, but “cloaked” by the caregiver in an embracing manner (Jaiswal, Alici & Breitbart, 2014:87). Palliative Care (PC) is defined by the World Health Organisation (WHO) as an approach that aims to improve the quality of life of patients with life threatening illnesses and their families. This is achieved by the prevention and relief of suffering using rigorous assessment, management of pain and treatment of other holistic problems such as physical, psychosocial and spiritual suffering (World Health Organisation [WHO], 2019b).

The palliative care approach is one that has evolved over the years from only focusing on the comfort of patients to including the focus on symptom control and support right up to the bereavement process after death. In between these, the focus is on the impact that life-threatening illnesses have on the psychological, social, spiritual and cultural aspects of the lives of patients and families (Jaiswal, Alici & Breitbart, 2014:87). The PC approach aims to improve quality of life through various ways, including, relief from distressing symptoms such as pain or other, treating the process of death as normal, allowing life to follow its course without attempting to postpone or hasten death, and integrating the aspects of psychological and spiritual needs into patient care (WHO, 2019b). The PC approach also creates a support network or system for the patient and their family whereby patients are encouraged to live as actively as possible until they reach the stage of death. This support network also works with families to help the family cope during the process of the patient’s illness and after death, during the bereavement phase (WHO, 2019b). It is argued that by doing all of this, quality of life will be enhanced and promoted, and that the course of illness may be more positive with comfortability of the patient and their family. It is also argued that PC can be used in early stages of illness when patients are receiving treatment to prolong life as a form of support for possible side effects and complications. PC uses a team approach to holistically deal with the various aspects which illness affects which as defined earlier, includes physical, psychosocial, and spiritual (WHO, 2019b).

PC aims to achieve a “good death” which consists of four components. Weisman (1972) in Jaiswal, Alici, and Breitbart (2014:88) indicates that these components include the reduction of internal conflicts such as the loss of control, the maintenance of the patient’s personal identity, the enhancement or maintenance of the relationships that are considered as important to the patient and the setting of goals that are meaningful and realistic that will achieve meaning and continuity for the patient. This theoretical framework is relative to the study as the participants in the study are expected to provide Palliative Care as part of their job description, which means that it is the framework from which they operate within and is standard of practice that they aim to achieve. This would mean that they would be consistently trying to promote quality of life and comfort through providing relief of physical symptoms, supporting the patient and family before and after death, and achieving a good death.

2.4 Positive aspects of working as a palliative care or hospice nurse

This section refers to the positive or enjoyable parts that professionals have identified in their work in the field of palliative care.

2.4.1 Feelings of being special

Palliative care nurses perceived that they had a calling and were destined to work in the field of death and dying. Due to the nature of the work, these nurses felt that their exposure to death and dying differentiated them from nurses in other fields and they perceived that they were special because not everybody can do this type of work (White & Gilstrap, 2016:307). Nurses working in palliative care have reflected that their knowledge and skills gained through their work resulted in them feeling valued and respected in their own communities (Penz & Duggleby, 2012:369).

In a study conducted with palliative care nurses, special qualities that they thought that they possessed included the ability to be present, open, balanced and self-aware. These nurses felt that these qualities differentiated them from other nurses and were likely why they were drawn to their role in the first place (Ellington et al., 2018:211). Other qualities that these nurses identified that differentiate them included having a sense of humour, an ability to be realistic while optimistic, flexibility and an ability to work independently when in the community as there are situations that are unpredictable (Penz & Duggleby, 2012:367).

It has been found that the palliative care field is more rewarding for nurses than other fields when they can make a difference in patients' lives by assisting them in reaching their goals in a limited time-span before death (Ablett & Jones, 2006:736; White & Gilstrap, 2016:307). In a study conducted with registered nurses providing palliative care in the community, it was found that these nurses were more hopeful about their work when they felt that they could make a difference. These differences pertained to the smaller scale with practical differences with family, or on a larger scale through the promotion of palliative care in the community. The same nurses expressed that at times when they felt that they could not see the difference they were making, it was important for them to know that they were trying their best (Penz & Duggleby, 2011:289).

Acknowledgement by patients and families also made nurses feel special, and overall, this helped nurses to feel that their work was meaningful (White & Gilstrap, 2016:307). Nurses in another study described that expressed gratitude from patients was especially valuable because appreciation continues to exist even though they are busy dying and may have other priorities, which reinforced the value that they were adding to patients' lives (Parola et al., 2018:184).

2.4.2 Feelings of honour and privilege

Many nurses feel honoured and privileged to work with dying patients for two main reasons. The first is that most nurses felt that these patients are often neglected and they are privileged to be part of a group that recognises the unique needs of these patients. This is a differentiating factor for nurses as they feel that not everybody is able to do this (White & Gilstrap, 2016:308). The second is that the nurses feel death is one of the most intimate and important moments in life and that they are privileged to share this moment with patients and families and potentially provide the opportunity for a good death for the patient and other forms of healing for the family at the end stage of life (White & Gilstrap, 2016:308; Sanso et al., 2015:204; Ablett & Jones, 2006:736). This identifies the large role that nurses think that they play at the end-stage of their patients' lives.

Nurses also described feeling that they were useful in patient's journey, giving them a sense of personal fulfilment and enrichment through the connected relationships that they establish, and they often have been made to feel part of the family. Feelings of connectedness and the enrichment of being part of, and making a difference in the patient's journey is something that

nurses have recognised as something that counteracted the emotional burden of their work (Parola et al., 2018:184; Penz & Duggleby, 2012:369).

2.4.3 Life Lessons Learnt

Working with dying patients appears to have provided nurses with lessons about their own lives. It has been found that nurses working in the palliative care field were more aware of their relationship with themselves (Parola et al., 2018:183) and in touch with their personal attitudes toward life and death, their own mortality and their spiritual being (Ablett & Jones, 2006:736). They have also found new meaning in life and practise existential coping through learning to be grateful and living meaningful lives by being present every day, and this has been perceived as positive (Chan et al., 2016:37).

Professionals working with dying patients also feel that they learn a lot from their patients (Fitch, DasGupta & Ford, 2016:68), for example, nurses feel that hospice work allows them to learn a lot about the process of dying and the intimacy of death which they could apply to their personal lives (White and Gilstrap, 2016:310) and spiritual conversations provided them with insight into their own faith and in some cases, strengthened it (Wittenberg, Ragan & Ferrell, 2017:569).

In studies conducted with palliative care workers, including nurses, it was found that these professionals, through their work, could acknowledge their mortality and therefore there was a higher sense of meaningfulness of life amongst these participants (Cheung et al., 2018:4; Parola et al., 2018:183). The awareness of their own mortality and vulnerability has lead nurses, in one study, to make changes in their interpersonal relationships, how they respond to conflict, and how they spend their time. They also expressed that they learnt to live more presently, worrying less about the future, focusing on their health and changing bad habits (Parola et al., 2018:183). This was achieved by acknowledging their own humanness through working with their patients (Parola et al., 2018:185).

The literature identifies the concept of post-traumatic growth (PTG) whereby if dealt with appropriately, professionals could have positive experiences of growth and change after exposure to trauma or highly challenging life experiences in their work, (Yilmaz, Üstün & Günügen, 2018:2; Itzhaki, Peles-Bortz, Kostitsky, Barnoy, Filshtinsky & Bluvstein, 2015:404).

PTG manifests through a richer spiritual life, more meaningful relationships, a greater perspective on life, a higher self-esteem, the adoption of new coping skills (Tedeschi & Calhoun, 2004, cited in Itzhaki et al., 2015:405), increased personal resources, a positive mood, and less distress, thus combatting burnout and compassion fatigue (Li, Cao, Cao & Liu, 2015:327; Yilmaz, Üstün & Günösen., 2018:2). In a study conducted with mental health nurses, it was found that they experienced above average levels of PTG despite exposure to violent and traumatic conditions with their patients, and that those who had experienced PTG were more satisfied with their lives overall (Itzhaki et al., 2015:409). Research conducted with oncology nurses found that when dealt with appropriately, trauma may serve as a catalyst for professionals to find meaning in their lives, and that there was a decrease in burn out and compassion fatigue despite nurses highly stressful occupation (Yilmaz, Üstün & Günösen., 2018:5-6).

2.5 Challenges that nurses in palliative and hospice care experience

2.5.1 Lack of training and education

Nurses in various studies identify a lack of training and education as a significant challenge in hospice and palliative care settings. It is said that professionals working in a palliative care setting who lack training constantly experience feelings of inadequacy and an extreme lack of control which increases stress and therefore puts them at higher risk for burnout (Cherny, Fallon & Kaasa, 2015:247).

Those providing palliative care identified a deficit in skills and knowledge as a challenge and found that it resulted in feelings of uncertainty and incompetence (Fen Chuah et al., 2017:23), a loss of confidence (Pearson, 2013:202) and an inability to effectively communicate with patients and families about illnesses and their prognosis (Chong & Abdullah, 2017:128). According to Hilding, Allvin and Blomberg (2018:2), cultural competency training is another need amongst palliative care nurses, as communication about death and dying is at the core of their work. It is indicated that an understanding of the patient and family's cultural framework and how this informs their understanding and response to death and dying is essential for nurses to understand so that they may communicate appropriately and effectively within the cultural framework of their patients and families. It is evident that there is a lack of training in palliative and end of life care globally and amongst all medical settings which serves as a challenge for nurses as it results in feelings of inadequacy and a lack of competence. Consistent with studies

internationally, a study conducted with critical care nurses in Egypt revealed that a lack of knowledge and training pertaining to good quality end of life care and how to support grieving family members was a significant challenge (Attia, Abd-Elaziz & Kandeel, 2012:299).

Palliative care training is in its infancy in South Africa, and up until the 2000s, there were no academic institutions offering any form of educational programmes in PC. A program was developed at the University of Cape Town in response to the World Health Organisation's request to begin to give PC recognition. Although this program is offered, PC as a specialisation remains limited in South Africa as it is a new, emerging specialisation (Ens et al., 2011:42). It is evident that there is a lack of training in palliative and end of life care globally and amongst all medical settings which serves as a challenge for nurses as it results in feelings of inadequacy and a lack of competence.

2.5.2 Emotional burden and distress

Emotional burden and distress have been identified as common theme in the literature pertaining to the nature of work, exposure to suffering and the impact on palliative health care workers on nurses' personal lives. It has been found that exposure to death and dying in the palliative care setting often leads to grief when the emotional experience of loss is not dealt with properly due to a lack of support and other stressors in the workplace (Funk, Peters & Rogers, 2017:3).

It was also found that employees in palliative care settings are also often exposed to suffering but were unable to alleviate this resulting in feelings of guilt and helplessness (Funk, Peters & Roger, 2017:3). A study conducted with nurses described this experience as a feeling of impotence (Parola et al., 2018:184) and in another study, this helplessness that health care workers experience was found to be related to lack of control over the dying process (Cheung et al., 2018:4). It was found that nurses were more likely to experience anxiety and distress than other professionals and this was suspected due to their role which includes case managing and facilitating sensitive conversations about death and dying (Cheung et al., 2018:5).

The personal expectations of workers also create an emotional burden in the palliative care setting. A study conducted in Malaysia found that palliative health care workers, including nurses, often experienced feelings of not having done enough, incompetence, helplessness,

powerlessness, and fear and anxiety when they could not fulfil patient wishes or alleviate suffering. Furthermore, they had experiences of loneliness and anxiety when they felt incompetent or helpless (Beng et al., 2015:21; Rattner & Berzoff, 2016:248-249).

Caring for the dying patient had negative consequences for palliative care health workers, who often found that they were emotionally drained after a day of work due to giving so much of self to patients and families. The result of this was that participants felt that they had nothing left to give to their personal relationships and that their personal and family life was often neglected (Fitch, DasGupta & Ford, 2016:69). Furthermore, participants in another study, with palliative care nurses, found that there was a challenge in terms of emotionally detaching from dying patients and their bereaved families and finding difficulty in switching off when they get home at the end of their working day, even if they know they have tried their best to alleviate the patient's suffering (Cheung et al., 2018:4-5; Parola et al., 2018:184; Reid, 2013:33).

In terms of grief and loss, nurses found that it was often their responsibility to support the bereaved family while needing to maintain professional boundaries despite their own sense of loss and what made this more difficult was a lack of understanding from management regarding this (Reid, 2013:33). However, in a study conducted by Penz and Duggleby (2012:370), it was found that the experience of grief and loss presented as particularly difficult for those working in the community as they feel that they become intimately involved with families and the patients, and their professional role becomes blurred due to this. Furthermore, in this same study, it was highlighted that nurses are exposed to multiple losses in the community as patients there are often short time spans between the deaths of their patients. It was also found that losses of patients sometimes triggered the nurses' own loss experiences in their personal lives. Other losses identified in this study pertained to losses of colleagues, changes in organisational structure and their own personal life changes (Penz & Duggleby, 2012:370).

2.5.3 Lack of support

According to the literature, many nurses in palliative care or hospice environments report that there is a lack of organisational support. In a study conducted by Whittaker, Kernohan and McLaughlin (2014:428), it was identified that there was limited formal support available to hospice nurses and informal support was used to substitute for this. Nurses feel that they are human beings with emotions and that a lack of support in the form of peer support and

debriefings did not allow them to deal with the impact of the demands of palliative care and left them feeling that their needs were unimportant (Penz & Duggleby, 2012:369). Other barriers such as staff shortages, a busy clinical environment and a lack of confidence prevented nurses from seeking adequate support, resulting in feelings of isolation and feelings of overwhelming responsibility (Pearson, 2013:199-204).

Organisational constraints, and a lack of management's understanding of the nurses' needs and their work is another challenge identified in the literature (Reid, 2013:33-35). Nurses providing palliative care in the community expressed feeling very isolated and identified that sometimes they felt unsupported by other professional colleagues and management/leaders (Penz & Duggleby, 2012:369). A lack of organisational resources such as equipment and staffing was a specific challenge identified by nurses working in the community, whereby they felt unable to provide a good quality service at home (Penz & Duggleby, 2012:368). A study conducted with palliative care health workers found that many of them did not know where to turn to for support, indicating that participants did not feel that they could seek support in their personal relationships as they felt that those outside of the field of palliative care did not understand the nature of the work (Fitch, DasGupta & Ford, 2016:68).

2.5.4 Demanding workload

A demanding workload is a major challenge amongst nurses providing palliative care to patients. Existing literature identifies that large workloads are a result of inadequate staffing and result in a lack of time when working with patients (Cherny, Fallon & Kaasa, 2015:247). The consequences of high workloads was that nurses felt that they could not fully or even partially attend to the needs of patient, and that this was further exacerbated by expectations of managers and organisational demands such as administrative duties (Beng et al., 2015:18). This created anger amongst palliative care employees as they feel that their high workloads have prevented them from helping patients as best as possible (Funk, Peters & Rogers, 2017:3).

In a study conducted in Malaysia with paediatric palliative care nurses, it was commonly reported that nurses found themselves having to juggle different demands due to their workload and were finding that there was insufficient time to do planned interventions as well as emergency or requested visits, therefore they could not complete all their work (Chong & Abdullah, 2017:128). Community Palliative Care nurses in another study described their

workloads as being overwhelming due to staff shortages, a lack of time, resulting in gaps in the service that they could provide as well as nurses feeling that their needs were unimportant (Penz & Duggleby, 2011:285; Penz & Duggleby, 2012:368-369). The workload stressors due to a lack of staffing and time for patient care is identified by Cherny, Fallon and Kaasa (2015:247) as a factor that could potentially lead to burnout. The final challenge for palliative nurses will now be discussed.

2.5.5 Challenging families

The family plays an important role at the end of life of the patient as they can facilitate the patient's needs and wishes being met, make the journey more meaningful, and gives them a feeling of being close to others (Hilding, Allvin & Blomberg, 2018:6). Family members often also take on a caregiving role to manage the physical needs such as administering medication and assisting daily routine tasks, and the emotional needs of patients, but express feeling ill equipped to undertake these responsibilities (Ellington et al., 2018:209). The needs identified in a study conducted with family caregivers receiving hospice services identified complex needs such as skilled communication, expert teaching and authentic relationships that improved their overall support experience from nurses (Ellington et al., 2018:212). Therefore, the need to support family is essential and equally important, however, this comes with its own set of significant challenges.

Palliative care nurses expressed that working with families in denial become problematic as well, as they are often unable to take information in, and establish a working relationship with the nurse (Hilding, Allvin & Blomberg, 2018:4). In another study, the denial that nurses identified that family members had were in relation to the severity and reality of the illness, and this denial was a coping mechanism used by families. This denial has proven to be very difficult for nurses as the process of working with families is found to be demanding and complex (Parola et al., 2018:184).

Another challenge identified was that at times, family members and patients would have different wishes and needs, or family members would disagree with the intervention proposed by the nurse and this posed as challenging for nurses (Hilding, Allvin & Blomberg, 2018:4; Reid, 2013:33). It was also found that nurses often found themselves in the middle of challenging family dynamics, and on the receiving end of misplaced anger whereby family

members may be angry at the situation or each other, and express that anger and frustration towards the nurses, who happen to be present at the time (Reid, 2013:33).

The above section demonstrated that nurses face many challenges in their work and the following section presents the literature pertaining to coping strategies that professionals, including nurses, have used to assist them with coping with these challenges.

2.6 Coping strategies of professionals providing palliative or hospice care

2.6.1 Use of social support

Social support and debriefing were found to be prominent coping strategies used by professionals in the field of palliative care to combat stress and burnout (Chong & Abdullah, 2017:129; Ablett & Jones, 2006:737; Whitebird et al., 2013:1537; McConnell, Scott & Porter, 2016:916). Social support has often been found in social networks outside of work or from colleagues at work in an informal capacity (Ablett & Jones, 2006:737). Palliative care nurses also used the team as a support structure which has been seen significant for them to cope with the demands of their work, as they could share the burden of care, express doubt and concerns, and share humour (Parola et al., 2018:185).

Debriefing has been found to assist professionals in feeling more equipped to provide good quality end of life care, however, the timing and nature of these sessions need to be appropriate, as when provided incorrectly could be found to prolong grief of professionals (McConnell, Scott & Porter, 2016:916). In Debriefing and receiving feedback from others assisted nurses to manage their work better and move forward with making a difference in their patients' lives (Penz & Duggleby, 2011:290), and provided them with an opportunity to reflect on how to equip themselves better to deal with losses in their work (Penz & Duggleby, 2012:370). Both social support and debriefing have been found to provide nurses with a sense of safety and guidance and that is why they have been used as successful personal coping strategies (Chong & Abdullah, 2017:129).

2.6.2 Self-care

Self-awareness in the physical, emotional, social and spiritual domains is an important component of self-care as it is argued that it is an essential tool needed in palliative care as through reflection and self-awareness, self-care can take place (Breiddal, 2012:6-12). Self-

care is defined as a personal maintenance strategy used to improve and restore wellbeing. There appear to be several forms of self-care identified in the literature, including regular physical exercise (Whitebird et al., 2015:1537; McConnell, Scott & Porter, 2016:915), a sense of humour (Ablett & Jones, 2006:737; McConnell, Scott & Porter, 2016:915), healthy eating, yoga and meditation (McConnell, Scott & Porter, 2016:915).

Engagement in self-care activities has assisted palliative care and hospice workers in coping and reducing incidences of compassion fatigue and burnout (Alkema, Linton & Davies, 2008:114), particularly due to the frequent exposure of death and dying (Sanzo et al., 2015:204).

2.6.3 Emotional distancing from clients

Professionals whom provide end of life care distance themselves from their cases as a method to cope and this is known as detachment (McConnell, Scott & Porter, 2016:915-916). In a study exploring grief in palliative care, although distancing was not found with all participants, it was found that distancing was used by some participants to avoid difficult feelings of grief, and the use of prevention of emotional attachment to patients, maintaining strong boundaries and remaining guarded allowed participants to cope better (Funk, Peters & Roger, 2017:5-6).

Other palliative care nurses expressed the difficulty in trying to manage their involvement in cases, stating the need to be present and the maintenance of professional boundaries, whilst needing to be emotionally detached (Reid, 2013:33). Palliative care nurses in another study identified this as challenging, saying that with some patients it was easier than with others, but felt that emotional distancing was a necessary strategy they used to protect themselves (Parola et al., 2018:183-184). Although it is a form of coping, detachment can also be a negative coping strategy as it often seen when compassion fatigue is present (Cherny, Fallon & Kaasa, 2015:253). Furthermore, emotional detachment has been raised as a concern by Reid (2013:35) as she found that this may compromise the quality of care that nurses are able to provide. Coping strategies are often personal forms of coping used by professionals, however unmet needs continue to exist and these will be identified as the next theme.

2.7 Needs of nurses providing palliative or hospice care

This section identifies the needs and recommendations that nurses and other palliative care professionals have suggested to assist them in coping with the demands of their work.

2.7.1 Education and training

The need for further education and training is a recommendation seen regularly in the literature pertaining to palliative care nursing. Oncology nurses in Qatar found that specific training needs, in order of priority, included communication strategies, psychosocial support, caring for dying patients, ethical and spiritual issues, symptom management, how to support the caregiver and pain management (Al-Kindi, Zeinah & Hassan, 2014:471). Recommendations by nurses in Egypt also included the development of specialised programs to better equip them with the skills to provide adequate support to patients at the end of life (Attia, Abd-Elaziz & Kandeel, 2012:303).

This is reinforced by McConnell, Scott and Porter (2016:916) as their study with staff in acute and community settings identifies training particularly pertaining to communication about end of life issues as an imperative need and strategy to improve confidence amongst end of life care workers. With this, a need for training in cultural competency was identified by Swedish nurses which would also assist with effective communication was identified (Hilding, Allvin & Blomberg, 2018:2). Palliative Care professionals, including nurses identified another training need as learning the skills to manage their emotions more appropriately in response to their patients and families, especially after a death. Recommendations such as the use of role-playing that assists them to build self-awareness in realistic situations were made (Cheung et al., 2018:5). Grief training was also identified as a need by nurses in another study conducted by (Lobb et al., 2010:229).

Further recommendations in a study conducted in the United Kingdom in terms of skills training, identified the need for closer clinical supervision with an educational component, training in communicating effectively, better reflective practice and better working relationships between the professionals. These were recommended with the thinking that it would improve nurses' abilities to cope with the demands of their work and ultimately alleviate the impact of their grief (Reid, 2013:36).

2.7.2 Adequate organisational support

The need for peer support, debriefing and effective teamwork was identified by palliative health care workers when exploring potential support strategies (Fitch, DasGupta & Ford, 2016:71). Nurses in a study conducted by Lobb et al. (2010:228-231) recommended that debriefing should be structured to focus on the personal impact of their work, as well as case supervision focusing on both the medical and psychosocial aspects of their care. In terms of time, nurses wanted debriefing which was available regularly, and immediately if necessary. These same nurses also felt that they would benefit from bereavement counselling (Lobb et al., 2010:229).

Other studies have found that a request from nurses is the provision of formalised clinical supervision and support within organisations (Pearson, 2013:206; Morgan, 2016:40; McConnell, Scott & Porter, 2016:916), that is non-judgemental and safe (Pearson, 2013:206) and that compassion satisfaction is linked to adequate organisational support for staff (Yu, Jiang & Shen, 2016:37). Further types of organisational support identified were short time-out sessions that afford staff to reboot emotionally in between seeing patients (McConnell, Scott & Porter, 2016:916) and the provision of opportunities for self-care in the form of complementary therapies such as massage from the organisation (Whitebird et al., 2013:1537; Lobb et al., 2010:232). The combination of supervision, counselling and complementary therapies was recommended by community based palliative care nurses to reduce stress levels and incidences of burnout (Lobb et al., 2010:232).

2.7.3 Acknowledgement and reward

The literature indicates that health care workers in palliative care settings felt that acknowledgement of the difficult nature of the work by managers would assist them to feel more supported (Fitch, DasGupta & Ford, 2016:71), and that the provision of support to clinical staff is a form of acknowledgement and reward (Cherny, Fallon & Kaasa, 2015:248). It has also been found that acknowledgement can also be provided in the form of adequate financial reward, as inadequate financial reward can lead to burnout as employees feel undervalued by their organisations (Cherny, Fallon & Kaasa, 2015:248).

Research conducted with palliative care nurses identified that when participants felt appreciated or acknowledged for the work they were doing, they felt more motivated and could provide a better-quality service to patients (Parola et al., 2018:185), thus indicating the importance of ensuring that nurses are acknowledged and rewarded by their organisations for the work that they are doing.

2.8 Conclusion

This chapter presented the legislation and policy, underpinning theoretical frameworks, and the existing body of literature that is relevant to the objectives of the study. From the literature, it is evident that whilst working in the field of palliative care may be very rewarding, it also comes with potentially significant challenges. The literature identifies potential mechanisms to assist with these challenges and these were highlighted. The next chapter will discuss the research methodology.

CHAPTER THREE

METHODOLOGY

3.1 Introduction

This chapter will discuss the methodology that was used to conduct the research. This includes the research design, sampling, data collection, data analysis, data verification, and limitations. A conclusion will complete the chapter.

3.2 Research design

This study was conducted using a qualitative research design. Qualitative research is described as an inductive research approach that is conducted in a natural setting and is focused on gaining an in-depth understanding of human behaviour in a specific context (Babbie & Mouton, 2001:270). The aim of a qualitative approach is to understand, describe and interpret human behaviour as opposed to predicting and explaining it (Babbie & Mouton, 2001:53). Qualitative research is said to use words as data, and although data is limited, it is said to be rich with “thick” descriptions of phenomena which numbers do not capture (Braun & Clarke, 2013:4; Babbie & Mouton, 2001:270).

A qualitative approach was used to focus on and emphasise the participants’ experiences and perceptions in ways that were rich and meaningful. The nature of the research required an approach which was exploratory of the experiences of the nurses in their professional capacity. Exploratory research is used to gain insight into a problem or topic, rather than test a hypothesis (de Vos et al., 2005:106-116), and provides the researcher with a broader understanding of a specific community, and how they make meaning of their circumstances (Engel & Schutt cited in Strydom, 2013:151). This study was not intending to establish facts or one objective reality, but instead, was particularly interested in the unique experiences of community-based nurses who provide palliative care to patients and their families at home.

A qualitative, exploratory approach allowed the researcher to not only identify what these experiences of their work were, but the more in-depth and personal reasons and perceptions that lead to these experiences that the participants described. Thus, allowing space for diversity in findings, but also an opportunity to identify commonly shared themes and experiences amongst the participants. Participants also reflected that the nature of the interviews was

personal and resulted in them feeling heard. Furthermore, an explorative research design was used in this study to gain new insight into the unique experiences, of nurses working in the field of palliative care in the South African context.

3.3 Sampling

Due to the nature of qualitative studies, whereby the researcher hopes to explore subjective, in-depth experiences and perceptions of participants, the sample group is dependent on what the researcher is interested in (Strydom & Delport, 2011:391). According to Sarantakos (2000) in Strydom and Delport (2011:391), qualitative sampling is low cost, somewhat limited, and non-representative, which results in non-probability sampling being used primarily. The type of non-probability sampling that was used in this study was purposive sampling. Purposive sampling refers to choosing a specific sample that possesses the specific characteristics that are relevant to the study that the researcher wishes to conduct (Babbie & Mouton, 2001:166).

Initially, the sample group in this study was nurses based in the greater Cape Town area whom provide palliative care in the community on behalf of St Luke's Combined Hospices. Sample selection criteria did not consider age, experience and gender although there were not any male participants as at the time of the study, there were no male registered nurses working at St Luke's Combined Hospices. There was a total of 18 nurses employed permanently and two locum nurses, but two nurses were excluded as they work closely with the researcher and were used for the pilot study instead. Six permanent nurses and one locum nurse declined participation in the study, resulting in a final sample size of 10. The researcher gained consent from the St Luke's Combined Hospices Research Ethics Committee and Chief Executive Officer.

Once data collection was complete, the researcher felt that the sample size was too small. As there was the use of purposive sampling in this study, the researcher explored other organisations in the greater Cape Town area whereby the organisation possessed the specific characteristics relevant to the study and the existing sample. She identified Tygerberg Hospice as an appropriate organisation and gained consent from the Palliative Care manager of the organisation. The selection criteria at Tygerberg Hospice also did not consider age, experience and gender. There was a total of five palliative care nurses working in the community who were employed at the time of the study, and four of these nurses participated voluntarily. Thus,

leading to a final sample size of 14 ranging in age, experience, however, all participants were female.

3.4 Data collection

3.4.1 Pilot study

A pilot study is used in the research process as it allows the researcher to test questions and gain clarity pertaining to the feasibility of the interview schedule. This information will allow for relevant modifications, if necessary, to the schedule so that it is able to gain the best quality data (de Vos, Strydom, Schulze & Patel, 2011:23). Two nurses at St Luke's Combined Hospices whom work in the False Bay area and are also providing palliative care to patients and families in the community were interviewed for the pilot study. These nurses are colleagues of the researcher and were excluded from the study's sample as they work in the same community as the researcher, but were appropriate for the pilot study to test the interview schedule. Once the pilot study was complete, minimal alteration was needed as the researcher simply needed to rephrase and re-order some of the questions.

3.4.2 Data collection approach

Interviewing is the most common method of data collection in qualitative research (Greeff, 2011:342) and one-to-one interviewing is one type of interview that is often used (Greeff, 2011:347). This study used one-to-one interviewing, with semi-structured interviews as its method of data collection. One-to-one semi structured interviews are flexible but organised around a topic of interest and allows the researcher to gain perceptions and beliefs of the participants about the topic (de Vos et al., 2005:292-296). Questions are mostly open ended and the approach of semi-structured interviews views the participant as the expert (de Vos et al., 2005:296). There were two phases of data collection in this study, with ten semi-structured interviews conducted over a period of approximately one month initially. One month later, another four semi-structured interviews were conducted in one day. The total period of data collection lasted approximately two months. The duration of the interviews ranged up to 90 minutes, depending on the participants' willingness to share. Participants were given a choice as to when and where they wanted to be interviewed and this included their homes. Most participants were comfortable to be interviewed at their place of work in a private office. However, there were two participants who requested to be interviewed at their homes.

3.4.3 Data collection tool

A semi-structured interview schedule was used as the tool to collect data. Smith and Bowers-Brown (2017:9-10) explain that a semi-structured interview schedule is a set of predetermined questions that guide the interview, however, there is space for flexibility to allow the researcher to specifically explore and probe the participants' responses. This allows the space for unique and in-depth experiences to be raised and discussed. In this approach, it is important that the interviewer is somewhat skilled in conducting interviews that require improvisation and the interviewer should possess the ability to identify moments in which to explore and probe (Smith & Bowers-Brown, 2017:10). A semi-structured interview schedule requires time and effort to compile, however, the advantage of it is that it encourages the researcher to reflect on what they hope to gain and what challenges may arise in the interview, and this enables the researcher to enter the research interview more prepared (Greeff, 2011:352). In this study, the research questions were used as a guide to create the interview schedule (see Appendix C), as stated previously, the interview schedule was tested in the pilot study and adjusted where necessary to best extract answers relevant to the research questions and objectives. As a result, the researcher could conduct an interview that was relevant to the topic of interest.

3.4.4 Data collection apparatus

According to Greeff (2011:359), if the researcher obtains permission from participants, a tape or video recorder should be used during interviews as it allows for a more detailed record of the interview as opposed to written notes. Two tape recorders were used when interviewing the participants as it assisted the researcher to be present and engage with the participants easily and on a more personal level. This was particularly important due to the sensitivity of the material that may have arisen in the interviews. It also allowed the researcher to explore and probe when necessary, without the concern of missing anything. Recordings of the interviews also improved the reliability of the study as the researcher could play back the audio interviews and become more familiar with the data, and data analysis was conducted on verbatim transcriptions of all 14 interviews. The use of the tape recorders was discussed when the participant was signing the consent form (see Appendix A, section 4), and through the signing of the consent form the researcher was given permission to use the data collection apparatus.

3.5 Data analysis

This study used Tesch's (1990) eight step model for data analysis as presented in Creswell (2014). Once the interviews were conducted, the audio recordings were transcribed by a contracted transcriber, and then analysed by the researcher, who then arranged findings into themes, categories and sub-categories as prescribed by Tesch's (1990) model. The primary tasks for each step were followed by the researcher:

- i) The researcher read through the transcribed interviews and listened to the audio recordings, paying attention to similarities and patterns.
- ii) The researcher then began to label and highlight emerging themes or topics in the text.
- iii) Steps i and ii were applied to all the transcripts and topics were clustered together into initial themes, categories and sub-categories.
- iv) A coding framework of the data was then created by the researcher, and if any new topics emerged, they were added to the existing structure.
- v) The researcher then found the most appropriate descriptions for each theme, category and sub-category with names that best described their content.
- vi) Final decisions regarding categories were made and listed alphabetically.
- vii) The researcher performed a preliminary analysis by collating and assembling the data relevant to each category, and this was done for each category.
- viii) Where necessary, the researcher recoded the existing data.

3.6 Data verification

Data verification refers to the quality of the research, and Lincoln and Guba (1999) in Schurink, Fouché and de Vos (2011:419-421) and Babbie and Mouton (2001:277-278) introduce four criteria to ensure that the research is truthful and of good quality. These are as follows:

Credibility/Authenticity refers to whether participants' contribution to the research were represented accurately, with the need for a match between the two (Schurink, Fouché & de Vos, 2011:419). In this study, data analysis was conducted using a framework which guided the researcher's steps to analysing the data appropriately, thereby accurately presenting the data. The use of the tape recorder also assisted the researcher to be as accurate as possible. **Transferability** refers to whether the data can be generalised. It is argued that generalising qualitative studies is challenging as subjective, personal experiences are explored, however, this can be countered by linking findings back to the literature (Schurink, Fouché & de Vos,

2011:420). This study used a deductive approach in part when analysing the data and through linking the data back to the literature, some of this data could be transferable. The use of purposive sampling where the sample is specifically selected due to their relevant role within the topic also assists with transferability of the data (Babbie & Mouton, 2001:277). Purposive sampling was used in this study as a method of securing transferability of the data.

Dependability refers to whether the outcomes and findings of this study would be the same, if the study were to be repeated using the same steps. Lincoln and Guba in Babbie and Mouton (2001:278) argue that if a study is credible it is therefore dependable and that by demonstrating credibility of a study, dependability is secured and does not need to be demonstrated separately. This study will demonstrate credibility to ensure dependability. **Confirmability** considers the researcher's own viewpoint and bias. For confirmability to be secured, the study needs to reflect the data in a way that it is not influenced by the researcher's biases. The process of data analysis should be reviewed and audited if necessary (Babbie & Mouton, 2001:278). Prior to conducting the study, the researcher was aware of her own biases, and how they could affect the outcome of the study. Furthermore, a trail of raw data, any products used in data reduction, analysis, and data reconstruction, and any other relevant tools or notes used in the data analysis phase have been provided as suggested by Babbie and Mouton (2001:278).

3.7 Inherent limitations

According to Fouché and Delport (2011:111), limitations are commonly found in even the most meticulously planned research studies and should therefore be acknowledged. The inherent limitations of the study pertain to:

3.7.1 Research design

Schurink, Fouché and de Vos (2011:420) state that qualitative research is difficult to generalise due to a small sample group. This is viewed as a limitation; however, it is argued that generalising the research is not the purpose qualitative research. The purpose of this study was to explore and understand the specific experiences, perceptions and subjective realities of the participants, and using a qualitative approach allowed the researcher to do this.

3.7.2 Sampling

There were three main issues of sampling identified in this study, the first was the size of the sample. According to Schurink, Fouché and de Vos (2011:420), small samples are difficult to generalise. However, the purpose of this study was to explore the in-depth and unique experiences of the participants, rather than to generalise.

The second issue was that the study was conducted at two research settings, and there were ten participants from one organisation, and four from the other. The researcher ensured that despite being from different organisations, the role of the participants within their organisations were similar in that they all provided palliative care to patients and their families at home in their capacity as a nurse.

The third, and final sampling issue was that during the time of the study, one of the organisations were going through a time of transition and change and this may have affected their perceptions of organisational support and feelings of safety, as well as their willingness to be open and honest during the interviews. However, organisational change and transition contributes to the experiences that nurses have in their work and lead to valuable findings in the study.

3.7.3 Data collection approach

Limitations of one-to-one interviews include that participants are unwilling to share or are more likely be dishonest with their responses. Furthermore, the questions posed to the participants may not elicit the responses that the researcher is seeking (Greeff, 2011:360). The researcher encouraged participants to share openly, assured confidentiality and was non-judgemental so that they felt willing and secure to share honestly. A pilot study was also conducted, and questions were modified as best as possible to elicit appropriate responses.

3.7.4 Data collection tool

It is important that semi-structured interviews remain flexible to extract rich data (Greeff, 2011:351-352). Validity and reliability needs to be ensured with regards to the data collection tool (Delpont & Roestenburg, 2011:172-177), thus, if the interview is too rigid, and the researcher lacks flexibility as required by a semi-structured interview schedule, meaningful data may be neglected and the tool will lose its validity and reliability. The researcher made

use of the semi-structured interview schedule but asked further questions and probed when pertinent. The pilot study assisted the researcher to practise the use of the semi-structured interview schedule and this allowed the researcher to be flexible during the interviews and probe where necessary, ultimately eliciting in-depth and more meaningful responses.

3.7.5 Data collection apparatus

According to Greeff (2011:359), the use of a tape recorder presents with challenges as it could make participants uncomfortable during the interview and make them question confidentiality. When requesting their consent to participate in the study, the researcher discussed the purpose of using a tape recorder with participants and were informed that only the researcher, her supervisor, the transcriber and the examiners would have access to the audio recordings. Participants were also ensured that data would be stored safely on a password protected platform for up to one year after the data collection interviews and would be destroyed thereafter. All 14 participants consented to the use of the tape recorder (see Appendix A, section 4) and did not appear to be uncomfortable with the use of it during the interviews.

3.7.6 Researcher bias

The researcher's role should be identified before conducting the study, and this includes their connection to the topic and whether there is any potential bias, especially if the research is conducted in his or her organisation. Furthermore, the researcher needs to be aware that interviews with close colleagues may affect the data that arises in the interviews (Creswell, 2014). The researcher works in the field and one of the organisations where the study was conducted. Researcher bias was managed through the management of her dual-role, the use of academic supervision and regular reflection. The research was conducted with nurses working in different communities and these participants, although familiar with the researcher, signed consent that they understood that the researcher was interviewing them in her capacity of a researcher rather than employee. Discussions about potential researcher bias, managing the dual role and conversations about the researcher's ability to manage the interviews professionally were also had with the researcher's supervisor before data collection took place.

3.8 Conclusion

This chapter discussed the methodology used in this study pertaining to the research design, sampling, data collection, data analysis and limitations. The penultimate chapter will present the findings of the study conducted.

CHAPTER FOUR

RESEARCH FINDINGS

4.1 Introduction

This chapter discusses the findings of the study. A profile of the participants and a framework for the findings will be presented. Thereafter, the findings of the study will be discussed in the context of the research objectives.

4.2 Profile of the participants

Table 1: Profile of participants

	Age	Gender	Marital status	No. of children	Nursing ranking	Years at organisation
Participant 1	53	Female	Married	2	Staff nurse	1 year & 3 weeks
Participant 2	58	Female	Married	1	Registered nurse	11 years
Participant 3	54	Female	Divorced	2	Registered nurse	8 years
Participant 4	69	Female	Divorced	0	Registered nurse	3 years
Participant 5	59	Female	Single	0	Registered nurse	15 years
Participant 6	66	Female	Married	2	Registered nurse	4 years
Participant 7	68	Female	Married	2	Registered nurse	5 years
Participant 8	58	Female	Married	3	Registered nurse	5 years
Participant 9	67	Female	Divorced	4	Registered nurse	5 years
Participant 10	58	Female	Divorced	3	Registered nurse	3 years
Participant 11	67	Female	Divorced	2	Registered nurse	20 years
Participant 12	46	Female	Married	3	Registered nurse	15 years
Participant 13	71	Female	Married	2	Registered nurse	4 years
Participant 14	70	Female	Widow	2	Registered nurse	14 years

The above table is a representation of all the participants who participated in the study. To ensure anonymity, each participant was assigned a participant number randomly, and these will be used as pseudonyms when using quotations. In terms of the demographics of the participants, all the participants were female with an age range of 56 to 71 years old. Their marital statuses varied, and most of the participants had children. Most participants' nursing ranking was registered nurse, with one exception of a staff nurse, and the years worked at their organisation ranged from one to twenty years.

4.3 Framework for discussion of findings

The following table presents a framework of the findings, organised according to themes, categories and sub-categories.

Table 2: Framework of findings

THEMES	CATEGORIES	SUB-CATEGORIES
Positive Aspects of Working in Palliative Care	Patient and family contact	Feelings of honour and privilege Making a difference Appreciation from patients and families
	Personal gain	Life lessons learnt Role in the community
	Working in a team	
Challenges experienced	Emotional burden	Persistent rumination about work Feelings of helplessness Challenging families
	Negative personal consequences	Poor physical health Negative consequences on family life
	Organisational challenges	Demanding workload and administration Lack of support from organisation
	Difficulties of working in the community	Safety Driving to patients
Current Coping Strategies Employed by the Nurses	Personal strategies	Family and friends Avoidance coping Self-care
	Availability of organisational support	Group support/debriefing Colleague support
Recommendations to organisation to assist in coping with demands of work	Staff Support	One-on-one open-door policy for advice and debriefing Training and education
	A better understanding of what community based palliative care entails	
	Interaction with staff	
	Staff Reward and Recognition	Appreciating and valuing staff Salary reviews

4.4 Discussion of findings

The findings of the research will be discussed according to the research objectives of this study.

4.4.1 Objective 1: To explore the positive aspects that palliative care nurses experience in their work

This section will focus on the positive aspects of working in palliative care. The findings indicate that these are in relation to patient and family contact, personal gain and working in a team.

4.4.1.1 Patient and family contact

Patient and family contact refers to the positive experiences that the participants of the study experience in terms of feelings of honour and privilege, making a difference and receiving appreciation from patients and families.

4.4.1.1.1 Feelings of honour and privilege

An aspect of patient and family contact that most participants enjoy is building relationships with different patients and families, and they feel honoured and privileged to be accepted into patients' personal space and being part of their journey.

Participant 3: *"I love meeting the variety of people that I do. Umm... really I do see it as a huge privilege getting, you know, into that personal space with people".*

Participant 11: *"I love my patient contact. Ya, I love, umm, I love preparing my families for, for the dying process. For me, being close to a dying person is a very precious experience. To be part of that person's journey, you know, their last, last journey... You can just stroke them nicely, 'cause they've learnt to trust you, and you've built a relationship, and they're comfortable with you and can tell you anything".*

It is evident that some participants have found value in getting to know their patients and families intimately, through gaining their trust and walking their journey with them. This is consistent with the literature which has highlighted how palliative care nurses feel honoured

and privileged to walk the journeys with their patients, potentially assisting them in having a good death (White & Gilstrap, 2016:308; Sanso et al., 2015:204; Ablett & Jones, 2006:736), and a sense of personal fulfilment and enrichment (Parola et al., 2018:184; Penz & Duggleby, 2012:369).

4.4.1.1.2 Making a difference

Many participants in this study felt that their input with patients and families made a difference to their lives at this particularly stressful time, and they enjoyed being able to see the results of their intervention, whether this was practically or in patients' emotional and spiritual journey.

Participant 9: *"Oh, my most part I enjoy is actually assisting, supporting the patient. To be there for them when they need me, and I actually really enjoy that. When I can see there's change... When I can see people are getting better... they're doing something about their lifestyle... and just the fact that they at peace and actually also to enjoy their life while they can still enjoy it".*

Participant 1: *"...maybe you didn't make a difference to the condition, but just the fact that there's somebody with experience that they rely on, and they'll say, "Oh, I see, it makes sense." So I do enjoy, because it means that I do play a good role in the, in the healing – or I wouldn't say healing, because we know palliative care patients are dying – but just the, the progress of the patient".*

The above findings concur with the literature that has identified how nurses' job is more rewarding through being able to make a difference (Ablett & Jones, 2006:736; White & Gilstrap, 2016:307), and resulting in them having more hope about the field that they're working in (Penz & Duggleby, 2011:289). The study also identified that participants expressed feelings of being special because of their ability to make a difference as evident in the quotes below.

Participant 6: *"it's like a, it's like you're an angel, man. You make everything right".*

Participant 8: *"...and they can see you, not as a human, but as somebody who's a Florence Nightingale who can just come and smile and make a difference".*

The participants in this study indicated that making a difference has enabled them to feel that they are contributing to the patient's journey whereby they are able to enjoy their lives and have some form of wellness despite being terminally ill, resulting in the participants feeling that they are special and unique for being able to do this. These findings support the literature where nurses felt they were different and destined to work in this field because they had something unique to offer that differentiated them from other nurses working in different fields (White & Gilstrap, 2016:307).

4.4.1.1.3 Appreciation from patients and families

Many participants in this study identified that a positive aspect of their work is the appreciation that they receive from patients and families, and they find it rewarding. Appreciation was identified as being thanked by patients and for their contribution, and it appeared to be a form of recognition of their input.

Participant 14: *"I think... you know, in a strange way, when patients say "thank you" – I don't mean in a you know, not by any other way but just being grateful that you actually visit – makes it very rewarding".*

Participant 11: *"The, the fulfilment and the precious moments... and the gratitude. I brought a man into the ward on Thursday, and he was living in a, a youth shelter. I dunno why he was there 'cause he's 60 something... So I managed to get a bed and they were so kind – gave me a bed... and he got in the car and I really struggled to get him to the car – there were no wheelchairs or anything... and then he started to cry. So I said, you know, "Is it very sore?" 'cause he'd run out of morphine. Oh God it was awful. So he said no, the reason why he was crying was because I'd been so kind to him and he couldn't believe it, that people that didn't know him like me, and a different colour could worry about him and be so kind to him".*

These findings are consistent with the current literature, whereby nurses felt that appreciation from patients meant that their work is meaningful, and valuable (White & Gilstrap, 2016:307; Parola et al., 2018:184). It is evident that patient and family contact provides a positive working

experience for the participants in this study, however, personal gain from the work has been identified as a positive aspect of the work as well, and will be discussed below.

4.4.1.2 Personal gain

This study found that the participants felt that they have seen how working in palliative care has affected their personal lives in terms of what they have gained through their work. This will be discussed with regards to life lessons learnt and their role in their communities.

4.4.1.2.1 Life lessons learnt

Most of the participants in the study expressed that they have learnt life lessons through their work, which they found to be a positive experience, adding value to their personal lives. Some of these life lessons pertained to relationships, whereby some participants feel that it is important to be mindful of what is important in their relationships, including their response to conflict.

Participant 13: *“I feel that I’ve grown a lot emotionally, and ah, ya, ya, and... in a sense that there’s a lot of soul searching for me”.*

Participant 3: *“...quite frankly I suppose I could also say, umm, the positive thing is I suppose also making one aware that actually its so, actually one realises like the petty things in life, actually... it makes you realise maybe in one’s own family, umm, you know, you must just let certain things... you know just let go. Try to let go of judgements and na, na, na... I mean, I learn from them, I learn with each family”.*

The literature also identified that nurses have made changes in their personal relationships after realising that life is finite, these changes included their response to conflict (Parola et al., 2018:183). Furthermore, some participants could identify how their work has strengthened their faith and spiritually, as demonstrated below.

Participant 12: *“Umm, spiritually, I think umm, I’ve become more umm, aware of how we need to forgive and not to, to harbour unforgiveness or bitterness... Umm, especially to the end of life and umm that has made me more aware of my journey”.*

Participant 9: *“...I see nursing as my calling, so umm, what I do, I enjoy, and it help [sic] me also to grow spiritually, and it keep [sic] me focused... sometimes you neglect yourself. You’re so good to help others but not yourself. But many times I sit and do reflection. I actually apply the things and advice I give to others in my own life as well”.*

These findings concur with the literature whereby palliative care professionals reported spiritual growth and strengthening, but also an awareness of their own journey of death due to the exposure to this in their work (White and Gilstrap, 2016:310; Wittenberg, Ragan & Ferrell, 2017:569). The literature also found that palliative care workers were more aware of their mortality and vulnerability in life (Cheung et al., 2018:4; Parola et al., 2018:183). In this study, some of the participants felt that they learnt more about appreciation of life because of insight into the fragility of life through their work.

Participant 7: *“I appreciate life more, ya, life, love... because there are times that you, yoh! But other people must go through... so yes it’s very... makes me more appreciate life”.*

Participant 13: *“You know where you... if you could turn the clock, you know, make a... change things and to things another way perhaps... other approach, you know...and also to appreciate other people, and you appreciate your life... and, and, and, your own surroundings. I mean, your own family.”*

Lastly, some participants reflected on positive ways of being, that they feel they have learnt through their work.

Participant 4: *“You know, I’m by nature a very intolerant person, and I think I’ve learnt to be more tolerant. I think because they role play that. They are tolerant of us in their space, and things happening to them”.*

Participant 1: *“In my personal... I’ve learnt to listen. I’ve learnt... that is really a skill that I didn’t have. I was very quick to jump and give advice. But now I’ve learnt to listen... and I become more relaxed because of that. Because I was always the one*

to solve problems. Listen and think it through... because the problem is still there but I'm more relaxed in my, my social life, my personal life, I've become more relaxed".

The findings of life lessons as a positive aspect of working in palliative is supported by the concept of post-traumatic growth (PTG) that is found in the literature, whereby nurses could have positive experiences of growth and change after exposure to trauma or highly challenging life experiences in their work (Yilmaz, Üstün & Günösen, 2018:2; Itzhaki, et al, 2015:404). These positive aspects manifest in more meaningful relationships, higher self-esteem, greater perspective on life, richer spirituality, new coping tools, increased personal resources, positive mood and less distress (Tedeschi & Calhoun, 2004, cited in Itzhaki et al., 2015:405; Li, Cao, Cao & Liu, 2015:327), thus, seeing an overall positive benefit as this leads to decrease in burnout and compassion fatigue (Yilmaz, Üstün & Günösen, 2018:2).

4.4.1.2.2 Role in the community

Several of the participants feel that their work has equipped them with knowledge and skills that have been perceived as valuable in their communities, and therefore they have found that they have gained respect in their own communities, and feel that they have been able to give back to their community in this way.

Participant 2: *"I can actually use this and apply it in my family. You know? Umm, and even in church also, people know what kind of work you're doing. They will always ask you, "****, come and see my aunt or brother or whoever." I'll just go... I don't have a problem. You have the skills... why do you want to keep it?"*

Participant 8: *"... if there's something going on there like – even if it's a ceremony, they had to come fetch me. Because I need to be there. For what I don't know. Just my presence makes them feel comfortable..."*

It is evident that the work that the participants' community members view them as having something to offer through the skills they have gained in their work, and this has been identified as a positive way in which their work has influenced other areas of their lives. The literature has identified this too, indicating that palliative care nurses feel that their knowledge and skills

from their work has resulted in feelings of respect and value from their community (Penz & Duggleby, 2012:369).

In terms of personal gain, Systems Theory supports the findings pertaining to personal gain (life lessons and role in the community), whereby Payne (2014:185), identifies that when an individual is impacted by one system, this impacts the other systems that they are part of. Exposure to what is happening in patient's relationships, spiritual journeys and ways of being at work (one system) teaches participants lessons which affect their behaviour in their other systems such as personal relationships and spirituality. It also helps them back to their community system whereby they can share their skills and knowledge with their community.

The personal gain of the work has been identified, however, other aspects required in palliative care, such as team work has been perceived as positive as well. This will be discussed next.

4.4.1.3 Working in a team

Working in a team was identified as positive by many of the participants, particularly in terms of some of the challenges experienced as discussed below, however, it appears that team work makes this more manageable because they can share the workload, and learn and support from each other, while prioritising the patient. A limited number of participants identified that challenges exist with colleagues when there is conflict or poor communication, but the overall sense was that working in a team proved to be a valuable experience for participants. In this study, the team refers to any persons involved in the management of the patient.

Participant 9: *"I have a good working relationship with staff is one thing that would help. I also enjoy certain staff members – I can debrief, talk, and discussion... because it's all about trust. So who can you trust and who can you share with. So it's a key thing for me... colleague support."*

Participant 1: *"...and I learnt a lot through working with social workers, my spiritual care people. It actually broadened my way of actually handling things. Like we went to – a scenario – I've been with one of my social workers, and how she handled the family, and the way she conducted the meeting with that fact, I learnt something from it".*

According to Palliative Care theory, working in an inter-disciplinary team is an essential, core component of palliative care (Paice, 2011:540-542; O'Connor, Fisher, & Guilfoyle, 2006:134), and these findings demonstrate how this approach is viewed as positive and valuable by some of the participants. The support aspect of the team will be discussed further under coping strategies.

This study's first objective was to identify the positive aspects of working in palliative care, and participants identified that they had a great sense of satisfaction from their work. There were several positive aspects to the work as discussed above, however, this study was also interested in the challenges experienced by community-based nurses working in palliative care, and this will be explored next.

4.4.2 Objective 2: To explore the challenges that palliative care nurses experience in their work

The challenges by participants experienced will be categorised according to the emotional burden of their work, the negative personal impact, organisational challenges and the difficulties of working in the community.

4.4.2.1 Emotional burden

The emotional burden of working in palliative care was identified by the participants in terms of their persistent rumination about work, feelings of helplessness and challenging families.

4.4.2.1.1 Persistent rumination about work

Persistent rumination about work was a challenge that more than two thirds of the participants identified, meaning that outside of work hours, they are either working or unable to stop thinking about some of their patients. The main reasons for this was due to bonding with the patients and/or families, trying to problem solve in their personal time, or feeling like the only person that the patient can rely on due to the practical nature of the work. The quotes below demonstrate how the participants struggle with this.

Participant 1: *“You connect with the patient and the family and you see the patient is dying. The family can’t accept it – you also want the patient to live because you*

feel this person's got so much to offer. Young patients very difficult for me to let go, I connect – sometimes I think I favour my young patients. I spend more time with them, I'm interacting more, and because I know they've got so much to offer still... and even to see the family let go – don't wanna let go. That is my – I would say the worst thing. Because when I go home I would lie, I'd lay and think, "What more can I do? What can I do to make it better?"

Participant 3: *"Ya, I suppose naturally you're going to be heart sore to patients that have formed a very good bond with you because it's natural. Some people you're just gonna have that connection. So it is kind of difficult umm... you know I did have a patient who I really connected well with and umm, it was like, it was a very intense road because there was also a lot of anxiety but it was also, it came together... and then you realise, okay hang, you know, this is... you know, now you must kind of try and sort of step away. You've gotta try and keep that balance. So ya, I'm... that can be very difficult when you are really fond of somebody and they maybe die. So that's naturally the loss, the loss".*

Participant 6: *"You know... if a hospital situation, you go off to your tea, you leave everything behind, there is staff on duty that can take over. Umm, they are qualified people so you don't have to take that home with you. But when you are the only person that's caring for these patients, you always come home and you think umm, you know, is that patient gonna be alright? That type of thing, so you always bring that thing with you... that you're worried, you know.*

These findings concur with the literature as it identifies that palliative care nurses ruminate about work at end of their working day despite trying their best to assist their patients (Cheung et al., 2018:4-5; Parola et al., 2018:184; Reid, 2013:33), The literature also found that in some cases, palliative care professionals use emotional distancing as a form of coping (McConnell, Scott and Porter, 2016:915-916; Funk, Peters & Roger, 2017:5-6), but that nurses specifically struggled with this (Reid, 2013:33). These findings also demonstrate System's Theory, whereby persistent rumination about work occurs in their personal time and while they are at home, thus negatively impacting their personal and family lives so what happens in the work system affects the personal system.

4.4.2.1.2 Feelings of helplessness

Several participants in this study, when reflecting on the difficulties of their work, expressed feelings of helplessness, and these feelings are often in relation to seeing how a situation could be easier for the patient and family, but there is resistance from the patient or family. Another form of helplessness that the participants experience is when they witness the socio-economic conditions that the patients live in, and they have no control over this.

Participant 2: *“There are times when they don’t even give us a chance. It’s their choice, it’s always their choice. I’ve ah, recommended that, I gave them information, you decide on that... and, and, and sometimes there are sad cases that you feel yoh, these people never gave me a chance. Even sometimes they, you don’t use the word death in the house. You can’t even umm, say cancer. You, you must just say about illness and that”.*

Participant 13: *“Especially in the community where I work. I work in a lower sub-economic... where there are things if, if better living conditions could improve this that and the other. I mean, not in our hands, but if I could make a difference in that sense.*

Feelings of helplessness pertaining to a lack of control over the patient’s dying process has been identified in the literature (Cheung et al., 2018:4), and the findings in this study support this, however, this study also finds that the South African context with its poor socio-economic conditions exacerbates feelings of helplessness because a lack of resources and how poor conditions affect the patient’s comfort. Furthermore, Palliative Care theory is an approach that these participants work from, and this approach might further exacerbate these feelings of helplessness as this places expectation to improve holistic quality of life for patients (WHO, 2019b), and when there are factors beyond their control, such as resistance, denial and poor socio-economic status, nurses may not feel that they are meeting this expectation.

4.4.2.1.3 Challenging families

Many participants identified challenging families as a significant challenge within their work for a range of reasons including demanding families whereby they have unrealistic expectations of the participants’ intervention and care. This makes it a challenge for the participants as they

struggle to set and maintain boundaries. Participants also found it challenging when there was a lack of consensus amongst patients and families, for reasons such as their needs being different, or denial of the family. This makes the participants' work challenging as they find themselves needing to balance the needs of families and patients

Participant 11: *"I do find sometimes when you've got family members that are very demanding. Umm, that does impact – when they're phoning all the time, and then I will say, "My work, my working hours are 8 to 4. Please respect that. I would really appreciate it, and ring me between those hours". Don't phone me at half past 9 at night 'cause I'm really not interested. I'm winding down, to go to bed".*

Participant 13: *"...and of course families can also be challenging because you...ya. But that you have to work around the families 'cause...the patients itself is comfortable, you know? Yes. Most of the time. But it's sometimes families that's not comfortable with the diagnosis, and with that, you know, so that is... families can also be challenging. Look, it's...because they sometimes can't accept the diagnosis, and deal with it, and also, if...if families feuds and things like that were not sorted out, you know? It's sometimes you find that...they leave it for the very last minute."*

The literature speaks to challenging families, and identifies similar challenges such as denial, different wishes and needs, and family dynamics as difficult (Parola et al., 2018:184; Hilding, Allvin & Blomberg, 2018:4; Reid, 2013:33). However, it has also been found that the family are an essential component in ensuring the patient is well cared for, but families often feel under-equipped and overwhelmed, and therefore it is imperative to support them and meet their needs. This is despite it being significantly challenging for palliative care nurses (Hilding, Allvin & Blomberg, 2018:6; Ellington et al., 2018:209-212). This indicates how a core component of a palliative care approach is supporting the family during the process of death and dying and bereavement (WHO, 2019b) which proves to be a significantly challenging task for nurses working in the field.

The emotional burden of the work provides an understanding of the perceived emotional demands as experienced by community-based palliative care nurses. The negative personal impact of the work is discussed below.

4.4.2.2 Negative personal consequences

Participants identified that working in community-based palliative care had a negative impact on them personally, specifically pertaining to their physical health and their family life.

4.4.2.2.1 Poor physical health

Several participants identified that their physical health has been affected by their work due to the demands and stress that they experience. They indicated that they have seen how stressful times at work have affected their sleeping patterns, eating habits and chronic health conditions.

Participant 12: *“Umm... it does sometimes also affect your health to the degree that you don’t sleep well at night because your brain is going at a rapid pace of what you’re going to do, what you still need to do... and you know, the week is perhaps short and how am I going to get through this, or sometimes there’s deadlines that needs to be met and because you don’t manage well, those things affect you because you then you become anxious, and sitting up all hours of the night because you need to complete these things... I’ve also had my blood pressure a bit higher than normal, umm, so I know, I know that it’s because there’s certain things that I’m not managing”.*

Participant 11: *“And, and the other thing that I’ve also realized is that I’ve put on a lot of weight, and, you know, I, I came home and – I don’t do it anymore – and I ate non-stop until I went to bed, and that - is also, it’s that stress. All the time”.*

Although the literature identifies the emotional impact of the work, the researcher did not find studies focusing on the impact on nurses’ physical health, however it is identified that the above-mentioned physical symptoms are sometimes evident in burnout or compassion fatigue which are conditions that seen amongst palliative care workers (Cherny, Fallon & Kaasa, 2015:162; Yu, Jiang & Shen, 2016:30).

4.4.2.2.2 Negative consequences on family life

The family lives of some of the participants have been affected negatively by their work, and participants expressed that their family must hear about their work at the end of the day, which

they are not always happy about. Furthermore, some participants expressed being too exhausted after their work days to be emotionally present with their families.

Participant 3: *“...not maybe giving enough attention to my own family. Not having the energy to umm, ya, my social life really went for a dive. Umm... but okay, umm, because the way I restore – If I can say find my balance and restore my, my energy – I kind of withdraw... I think... ya I need to withdraw, and then I don’t reach out enough to my family – keeping contact with my family. Ah, not having the, the energy to cope well with other stuff. I think because I’m, you know, you’re too drained and you get tired. I mean we, I think the sisters are kind of chronically tired”.*

Participant 12: *“...it’s your family time but you then start talking about this case that you’re dealing with and everybody else is sitting around the table and thinking, “Why should we be listening to this?”... It’s a way of debriefing for me to an extent, but it’s also at the cost of my family. Because that is not what they need right now... Or when you are irritated or frustrated with situations at work and you sometimes tend to bring that home, and you tend to bite somebody else’s head off and it’s got nothing to do with them but because of what they’re busy doing at the moment is causing a bit of extra frustration. You know you’d actually just go at them which is unfair, but it’s real and does happen”.*

The literature also identifies that participants’ family lives are affected by their work as nurses feel that they have nothing left to give to their personal relationships (Fitch, DasGupta & Ford, 2016:69). These findings also demonstrate what System’s Theory argues, whereby due to the emotional demands of the job, nurses are exhausted and their work system negatively affects their ability to be present in their family system (Payne, 2014:185). The negative personal impact of the work has been discussed, however, the participants in this study also identified organisational challenges in their work, which will be discussed below.

4.4.2.3 Organisational challenges

The participants in this study also identified organisational challenges such as conflict with colleagues, administration, workload, a lack of understanding and support from management and salary concerns.

4.4.2.3.1 Demanding workload and administration

Workload and administration was identified as a significant challenge by many of the participants. Staff shortages and high patient loads resulted in participants feeling overwhelmed and that their quality of care was compromised. While most of the participants could identify that it was necessary to do patient notes, they reported that there was a lot of extra unnecessary administrative tasks required, which was often time consuming. This was perceived as problematic because many participants found that they were either behind on administrative duties, which caused anxiety, or they were doing administration in their personal time and not being compensated for it.

Participant 9: *“Because my workload is seldom below 30 – my patient load. So we try to get through them all, and we wanting to make sure everyone’s okay. So we work without lunch, and that is a wrong thing. I mean, we shouldn’t be working without lunch – and we never claim it back... and even if you work after hours, you, you sit and you finish something here at the office, you don’t claim the time back – ‘cause it’s not your work hours”.*

Participant 14: *“I have more challenges with admin than I have with patients (laughs)... I’m very honest! The demands of admin – I find that quite daunting, because, I suppose in my heart of hearts – probably because I’m a nurse”.*

These findings are consistent with the literature whereby a demanding workload is a major challenge due to similar reasons such as patient loads, administration and a lack of time (Cherny, Fallon & Kaasa, 2015:247; Beng et al., 2015:18), also resulting in feelings of not being able to provide the best possible care (Funk, Peters & Rogers, 2017:3). Responding to this challenge appears to be important as the literature has found that nurses’ needs were not considered as important when their organisations overloaded them with work (Penz & Duggleby, 2011:285; Penz & Duggleby, 2012:368-369).

4.4.2.3.2 A lack of support from organisation

Participants expressed that they felt that there was a lack of support from their organisations, except for those who found group support useful, many expressed that they felt their organisations were doing little, or nothing, to support them.

Participant 9: *“Hoh! I don’t know at the moment. I don’t think that they’re there. I don’t know if they’re doing anything at the moment. Because at the moment, I don’t see any positive things for us as community sisters. I think maybe I’m blind that I can’t see it. But I can’t see or feel how the, the company’s protecting us”.*

Participant 7: *“Management is not really involved with us. Never involved with us. We would like them to also be more, you know, that concern or care about staff”.*

In some cases, there was support available but participants did not find it for useful or appropriate, as demonstrated below.

Participant 11: *“So, to sit in a support group today... There’s nothing wrong with me today. I’m absolutely fine, so what am I sitting here for? I’m wasting my time. Well, there sometimes, there, there’s groups. No, I don’t go to them. I find them a load of whinging, and, and I’m not into that”.*

The literature also found a lack of support as a challenge and that limited formal support resulted in palliative care nurses looking for support in informal settings, and often this lack of support resulted in feelings that they were unimportant (Whittaker, Kernohan & McLaughlin, 2014:428; Penz & Duggleby, 2012:369).

A range of organisational challenges have been identified, however, the participants in the study have also identified environmental challenges specifically pertaining to working in the community, and this is discussed below.

4.4.2.4 Difficulties of working in the community

4.4.2.4.1 Safety

The personal safety of participants was one of the biggest challenges identified by most of the participants, whereby they work in areas that have high crime rates. Participants reported feelings of anxiety and being on edge constantly when in the community and internal conflict regarding whether they should prioritise their own safety versus their patient's wellbeing. This is demonstrated below.

Participant 8: *“The building... there are no burglar bars, and the robbery happens in our doorstep there by the main gate. You know such things? And you're not safe”.*

Participant 6: *“But one also have to be wary about the dangers. You see, so that is a challenge... the dangers that's always around the corner”.*

Participant 10: *“Mmm...Yes, sometimes there are high-risk areas where you feel like...yoh! You don't like even to go and visit there...It's like that, mmm, unsafe”.*

The researcher did not find literature pertaining to safety challenges of palliative care workers, however, the personal safety of other professionals working in South African communities has become more publicised in recent years (Arrive Alive, 2018; Dano, 2017) and these findings are consistent with this. The safety concerns of the participants, as identified in this study, is especially important as it is evident that working in unsafe communities has negative effects on their mental health and overall wellbeing, and this opposes their right to a safe working environment that does not compromise their holistic wellbeing as outlined in the *Occupational Health and Safety Amendment Act, No. 181 of 1993*. The issue of nurses needing to choose between their own personal safety or the wellbeing of their patients and families appears to be a complex dilemma that could be researched further.

4.4.2.4.2 Driving to patients

Driving has appeared to be another challenge that community work posed for participants. The biggest challenges pertained to the volume of traffic and the large geographical areas they cover, which participants felt were tiring but also affected their ability to get to patients quickly in urgent situations.

Participant 11: *“If you asked me what the biggest problem of my day is, it’s negotiating the traffic. That’s what is it. The, the traffic, I think it wastes time, you get stuck... and then you’ve got somebody who’s desperate for you to come... so I find that traffic umm the... Umm, during certain periods, the traffic is really, really difficult... and I sometimes look at the end of the day – and I’ve had a helluva day – and I think, you’ve only seen 3 patients”.*

Participant 4: *“If you actually think geographically, the areas are enormous. So there is travelling... you can’t quickly get from one to the other”.*

Driving to patients is an issue that the researcher did not identify in the literature, however, it is an important finding as it indicates that the practical demands of working in the community needs to be explored further in terms of the negative impact of nurses.

The second objective of this study was to explore the challenging aspects of the participants’ work, and a range of challenges were identified. These included persistent rumination about their work, and feelings of helplessness due to factors out of their control. Participants also found that their physical health and family relationships were affected negatively due to their work. Demanding workloads and a lack of support from participants’ organisations were also experienced as challenging. Lastly, context-specific challenges were also identified as challenging. The following section will discuss the identified coping strategies used by the participants in response to challenges and difficulties in their work.

4.4.3 Objective 3: To understand the coping strategies that are used by these nurses to cope with their work.

This section will discuss the current coping strategies as practiced by the participants in this study and will be categorised and discussed according to personal strategies and the availability of organisational support.

4.4.3.1 Personal strategies

Personal strategies refer to the coping strategies created by the participants themselves which they have been personally responsible for, such as getting support from family and friends, avoidance coping, and self-care.

4.4.3.1.1 Family and friends

Participants in this study identified that family and friends assisted them in coping with their work in two main ways, the first was that they felt they could talk to friends or family about the demands of their work and receive support in this way. The second was that they could spend time with their friends and family and they experienced this as re-energising.

Participant 8: *“When I go home, I talk to my partner... and because my partner, husband is also a manager and he’s got skills that works on me as well. To say, “You know what? Maybe, maybe, maybe...” Then I’ll be fine. The support is here...is at home”.*

Participant 14: *“But I do have a couple of very good friends. We go to a flick and... you know? So it’s just ordinary, everyday things but umm... and over the weekend I do try and go out. Umm, I just go for drive with a friend or go visit somewhere I haven’t been or things like that”.*

The literature concurs and identifies this as social support as it was found that nurses accessed their social networks outside of work in an informal capacity for support and it was a coping mechanism that helped them to feel safe (Ablett & Jones, 2006:737; Chong & Abdullah, 2017:129).

4.4.3.1.2 Avoidance coping

Most participants identified the use of activities to escape as a form of coping with their work. When explored, the participants identified activities such as reading, going to theatre, listening to music and doing puzzles as activities that helped them manage their work better. This was a way for them to stop thinking about their work.

Participant 11: *“I think because you, it’s escapism, isn’t it? I...the, the novels that I read, they’re crime, I love it....the more disgusting they are, the better they are. Umm, 70’s, ‘80’s, you know 60’s...that kind of stuff. I like some of the modern stuff. But that... I’ve got two iPods. They travel with me wherever I go. and, and there’s that. And I like looking up stuff on the Internet. Umm, I like – I’m not very good at sending emails back – but I like looking at them, and umm, I also, I like doing word, like word searches, and I also play solitaire... and I, I realize I haven’t thought for ages. It’s just like a complete, almost cop-out”.*

Participant 5: *“Umm, and I read lot. Gardening I do a lot of, and I, I see the boyfriend over the weekends, so that’s something to look forward to and different, you know... I think it enables you to, to umm forget for a while - what you’re doing. It just puts you in a different space. and I go to the theatre a lot... Umm, so that’s like an escapism, ya, so once a month I round everybody up and off we go to the theatre or do something, you know. Yes...lovely. So those really help me”.*

The researcher did not find any studies finding avoidance coping as a coping mechanism used by nurses specifically to cope, however, in a study conducted with other professionals working under emotionally stressful conditions, it was found that avoidance coping, had negative results, ultimately leading to increased emotional exhaustion (Hershcovis, Cameron, Gervais, & Bozeman, 2018:170).

4.4.3.1.3 Self-care

Several participants identified self-care as a form of coping, in this study, the forms of self-care in this study were physical exercise, taking leave regularly, and even taking short breaks during the day to reflect and recollect.

Participant 12: *“Umm, I’ve also umm, been exercising more. Umm, which is, has been an absolute blessing to me. Because when I come back I feel that I’m in a better space, and it has made a difference to my health. I am sleeping better than what I used to. Umm, so yes, in that way it has it has made a difference, and I think I’ll umm, for me, of late, umm, I’ve become aware and not that I wasn’t aware previously but I think that our, our strength is that we know that we need to take care of*

ourselves. But our weakness is that we forget. Umm, so for me, when I am feeling stressed, when I am, I am a bit more aware. Now that I actually need - I need time out, and I need to do something that would help me. So either that I go for that walk. Either that I just have a 5 minutes before actually going home. That I connect with a friend, Umm, or just sit and, and breath before I go home or before I go to the next patient”.

Participant 5: *“I think, I think umm, ya...I try and do some exercise – just walking – I think that helps a lot... Umm, just to release stress. Umm, you know, I live on my own so I think I can control my environment - a lot better to, to cope with it”.*

The findings are supported by the literature and regular physical exercise, healthy eating, yoga, and meditation are identified as forms of self-care (Whitebird et al., 2015:1537; McConnell, Scott & Porter, 2016:915). The literature also stresses the importance of self-care to manage the demands of palliative care as it reduces the incidence of compassion fatigue and burnout (Alkema, Linton & Davies, 2008:114) and is a strategy that more participants in this study could potentially benefit from.

Although participants have employed a variety of personal coping strategies, some participants also identified that they have accessed organisational support to assist them to cope, and this will be discussed next.

4.4.3.2 Availability of organisational support

In terms of the findings of this study, availability of organisational support refers to support accessed within the organisation by participants to assist them to cope with their work. Group support/debriefing and colleague support was identified as forms of support within the organisation.

4.4.3.2.1 Group support/debriefing

Just less than half of the participant identified that when group support or group debriefing was available through their organisation, they made use of it and found it valuable as it was a space for them to share their difficulties pertaining to their work and receive support. Participants

also felt that the support groups made them feel less alone, as they realised that their colleagues were experiencing similar challenges and difficulties.

Participant 1: *“I have attended a session with our psychologist, and which was very good. Because there she said, you know, there we...we’ve got a group of 5 you’re not the only one facing with, sitting with this kinda of challenge in the workplace, so it makes it okay. I’m not complaining. Because umm.... So I think that support groups is very good, we call it a support group. Where we, it was for 6 weeks, running for 6 weeks. And we were looking forward. And what I learnt through that was to [know] my colleagues better, ya, so that’s also a coping method”.*

Participant 2: *“Well, I must say, they umm, they, the big thing that they have done for us is we also umm, get debriefing. There is a psychologist that will come every month and we will sit next to and everybody will say how they feel, and how they dealt with difficulty of the patients and the families... ya, it is helpful”.*

These findings concur with the literature, where palliative care workers identified debriefing as a helpful and successful coping mechanism as it provided them with support and guidance with cases (Penz & Duggleby, 2011:290; Chong & Abdullah, 2017:129), thus reinforcing the value of debriefing for these participants.

4.4.3.2.2 Colleague support

Colleague support has been considered valuable by most of the participants in this study, as colleagues are considered to provide an informal for of debriefing and support, advice and guidance on cases, and this enables participants to cope better.

Participant 3: *“So I enjoy that side. Also, you know, getting along well with colleagues, so that’s also a very nice side. Umm... It’s just that, the interaction, the support, sharing jokes, sharing experiences. Umm, it’s kind of like a debriefing that happens automatically... Which, you know, you might walk in and say, ‘You know, hey, this, this, that or the following,’ and they can give advice, or just anybody saying, “You know, ya, they understand this or that or the following”.*

Participant 7: *“Right in the beginning I suppose because I was not really sure whether I’m doing the right or the wrong thing. But by the help of my eh, Head of Department, and with my colleagues, that I’m more experienced. I also gained more experience, how to handle it, how to go about with challenging moments, so ya, that’s why I can cope now”.*

The literature supports these findings indicating that palliative care nurses used the team as structure for support as it assisted them in coping as they could share the burden of care, share humour and express their concerns about cases (Parola et al., 2018:185), again reinforcing how the use of an inter-disciplinary team in the Palliative Care approach theory fosters a sense of support for the participants.

The third objective of this study was to understand participants’ coping strategies. Several coping strategies were discussed. However, it was also found that many participants felt that there was a lack of support provided by their organisations especially with some participants identifying that they did not feel that there was any support at all. Therefore, the next section discusses the recommendations that the participants of this study have made to their organisation to assist them to cope with the demands of their work.

4.4.4 Objective 4: To ascertain the recommendations that nurses make to their organisation to improve their working experience.

The final section will explore the recommendations made by participants to their organisations to assist them in coping with the demands of their work. The recommendations will be discussed in terms of staff support, a better understanding of the work that they’re doing, interaction with staff, and reward and recognition.

4.4.4.1 Staff support

Staff support pertains to measures recommended by the participants to help them feel more able to do their jobs effectively. Staff support functions recommended in this study includes a one-on-one open door policy for debriefing, and further training and education.

4.4.4.1.1 One-on-one open door policy for advice and debriefing

A few participants felt that an individual open-door-policy may be helpful for them and recommended this to their organisation. The main motivation for this was that participants felt that the support that they are needing is often in the moment, either when they are with patients and need guidance or advice, or after difficult visits and they are needing to debrief immediately.

Participant 12: *“I would like to think that that umm, people, if, if they are struggling or – be it one of my peers – you know, with regards to umm, symptoms of patients, umm, that they could pick up the phone and just ask and say, “You know this is what I’m thinking, am I along the, the umm, along the right lines? Umm, do you think it’s... this is my, this is what I’m wanting to suggest. Have you had anything, an experience like this?” and be a support to peers in that way.”*

Participant 10: *“...an open-door policy. Mmm, like for instance you exercise like the channels of communication – I mean they’re right, but if maybe now there’s a dire need that I need to go see or I, I think I’ve got a right to go there. You know? It’s this sort of this... and then she must address it in a manner that you don’t feel at the end, “Oh, maybe I shouldn’t have gone there.””*

The literature also identifies a need for debriefing and identifies that this should be available regularly and immediately if necessary (Lobb et al., 2010:228-231), however, an open-door-policy, whereby participants can phone or speak to management about their stressors and the emotional effects of their work, as well as receive guidance at any time, is a new recommendation made in this study which was not identified in the literature review. The literature also identified a need for support in terms of bereavement counselling, adequate supervision (Lobb et al., 2010:229-232), and opportunities for self-care (Whitebird et al., 2013:1537; Lobb et al., 2010:232) which were recommendations that only a limited number of participants made in this study.

4.4.4.1.2 Training and education

Although a lack of training and education was not identified as a challenge in this study, recommendations for further training and education was made by some participants to assist them in feeling more skilled and equipped in providing palliative care.

Participant 13: *“...training, in, in this field that you are working... It’s to improve and for you also to improve perhaps your... the care that you give, that you provide for the patients... your skills perhaps”.*

Participant 5: *“We’ve asked and, and I’ve asked again today for some medical lectures. I mean the social work... they’re, they’re nice, but we personally as medical staff, need more stimulation. We need outside lecturers. We, we need – and we never get it.”*

Although this study did not explore the training needs of nurses in depth, it was still raised as a recommendation by participants, and the literature supports this as it identifies recommendations in training and education needs such as effective communication strategies about end of life, psychosocial issues, cultural competence, symptom control, how to support families and caregivers (Al-Kindi, Zeinah & Hassan, 2014:471; Attia, Abd-Elaziz & Kandeel, 2012:303; Hilding, Allvin & Blomberg, 2018:2). Recommendations such as learning the skills to manage the personal impact of the work was also made in the literature (Cheung et al., 2018:5; Lobb et al., 2010:229; Reid, 2013:36).

A lack of staff support has been identified as a recommendation by the participants and a few strategies for this have been identified above. The literature reinforces the need for adequate staff support as it has been found to increase compassion satisfaction (Yu, Jiang & Shen, 2016:37). The next recommendation was pertaining to managers having a better understanding of what community-based palliative care entails, and this will be discussed next.

4.4.4.2 A better understanding of what community based palliative care entails

Many participants feel that management and those in leadership positions do not have a good understanding of the work that they are doing and therefore made very direct recommendations,

encouraging management to come to the community and experience the community work for themselves, in order to gain a better understanding of the work.

Participant 4: *“Maybe that the manager of the community nurses does a few visits to (see) what is actually happening, and – cause remember the referrals are coming from the office, it’s a paper referral. The person there is not actually seeing what we find when we get there”.*

Participant 3: *“...ideally if one could hey, if, if they could... if, if each one could just know what the other person is dealing with in a day. You know, have more insight in everybody’s role... umm, understanding. I mean not everybody can go out with a sister to see what they are doing. But maybe they can even think of creating, I think that, that would be a marvellous idea. You know, somebody making a video on, you know, how, what... what does a day of a sister look, looks like... and then you can always, everybody can see each other’s role, and appreciate each other’s role, and know how to support each other”.*

The researcher did not find any other studies which identified the above. This could be because most of the studies in the literature are conducted internationally and nurses in the South African context face unique contextual challenges, as demonstrated in the quote below.

Participant 8: *“But if only they can make a time to come and sit like one-on-one and hear you out, because if you put in the paper, it’s not the same... like umm, maybe the safety, ne, the safety in our areas, and the equipment that we might need... that they could see that we really need this”.*

Participant 10: *“Mmm... Yes, sometimes there are high-risk areas where you feel like...yoh! You don’t like even to go and visit there... It’s like that... mmm, unsafe”.*

Participants felt that a better understanding of their work would help them to feel more supported, however, interaction with staff was also identified as a recommendation, which will be discussed next.

4.4.4.3 Interaction with staff

Participants in this study felt that interaction with staff, specifically pertaining to listening and consultation and earning trust and respect would assist them to cope with the demands of their work. Many participants expressed feeling that they were not listened to or consulted in terms of their needs and decisions made that impacted them, resulting in them feeling unsupported. This also resulted in staff feeling that their organisation lacked trust and respect for them.

Participant 1: *“I would have, umm... I would listen to, to the complaints, I would listen. I would go back and think about it and come back and ask, “How do you think we can release this, that, that?” There’s also, hear from the floor – what do they- I’m the manager, they on the floor. They doing the work, so I would want to know, “How do you think we can resolve this problem?” But I’m coming with a solution, and I don’t know what’s happening down there... So allow that – I will allow my staff to have input because they are the people doing the work”.*

Participant 6: *“We adults and, and you sit there in your office with degrees... so respect us for what we, you know?... I feel that they don’t ah, ah give us enough respect man”.*

Participant 3: *“So I would recommend that they must definitely trust the sisters and the way that they function. Not that you are trying to jippo your work or whatever. But you just know, okay, I’m saturated, I can’t anymore. You know, I need to go back home... and I can go back home, because I know the patients are A-okay”.*

The researcher did not find any studies that specifically address this finding however, it is acknowledged that this study was conducted during a transition period in one of the research settings, and these recommendations may be an indication of how staff members feel during a time of transition.

The nature of interaction with staff was identified as important and was recommended by the participants to their organisation. However, these participants also felt that reward and recognition would improve their working experience.

4.4.4.4 Staff reward and recognition

The participants in this study made recommendations pertaining to appreciating and valuing staff, as well as reviewing salaries.

4.4.4.4.1 Appreciating and valuing staff

When making recommendations, a few participants requested that they would like to be appreciated and valued by their organisation. Although they identified appreciation from patients as a positive aspect of their work, it appears that participants were feeling that there was a lack of acknowledgment from their organisation and provided some suggestions as to how their organisations could do this as demonstrated below.

Participant 3: *“Just giving that acknowledgement that you are also valuable. You’re valuable for your organisation... you kind of give staff credit. Like, you know, performed well for the week”.*

Participant 6: *“Give us more recognition man, for what we do. Because I feel we don’t really... You don’t want rewards but at least man, you know?... And just appreciate the nursing staff more... and this might sound petty, but when we’re there, at least let us be comfortable. You see how we all shift up in that small little area, all of us. We can’t even sit and have a cup of tea there decently. Half of the sisters must stand. Everybody’s in and out there, and no privacy for us”.*

The literature highlights that acknowledgement and reward of staff is important as they feel more supported (Fitch, DasGupta & Ford, 2016:71) but did not go into clearer suggestions of how this could be done, which is included in the findings of this study, However the literature indicates that appreciation is an important recommendation to consider.

4.4.4.4.2 Salary reviews

A few staff members expressed a desire for their organisations to review their salaries, indicating that it was an issue in terms of retaining staff, and that even though salary is not the only important factor in recognition, it was important to them.

Participant 4: *“A newly qualified nurse in a government hospital – not even in private – earns double than the hospice nurses do... and they don’t see that. Not all about the money, but it makes a lot of difference. I mean, what I’m earning, I couldn’t live on... They’ve gotta look at (it)... they’ll be able to retain staff.*

The literature indicates that one of the ways which staff can feel more acknowledged is through adequate financial reward and that inadequate financial reward has been seen to lead to burnout in some cases (Cherny, Fallon & Kaasa, 2015:248), therefore this is another important recommendation to consider.

The final objective of this study was to ascertain the recommendations made by participants to their organisations to improve their working experience. Participants felt that an open-door-policy for advice and debriefing would be a form of emotional support that was appropriate for the nature of their work. They also felt that receiving more training and education would help them feel more equipped to do their work. Participants also recommended that management should come into the community to gain a better understanding of the conditions that they work under. Furthermore, participants felt that respectful communication and consultation from management would improve their working experience. Lastly, it was indicated that more appreciation and salary reviews would help participants to feel more rewarded and recognised.

4.5 Conclusion

This chapter discussed the findings of this study using the research objectives as a framework. It was found that even though participants had an overall sense of satisfaction from their work, they still experienced emotional, personal, organisational and environmental challenges. Participants also provided insight into their coping strategies, but ultimately felt that their organisations could do more to support them, and thus provided specific recommendations to their organisations to improve their overall working experience. The final chapter presents conclusions pertaining to the study and makes recommendations for future research and to organisations working in this field.

CHAPTER FIVE

CONCLUSIONS AND RECOMMENDATIONS

5.1 Introduction

The final chapter discusses the main conclusions from the research according to the objectives of the study. The recommendations by the researcher are also provided for St Luke's Combined Hospices and Tygerberg Hospice, as well as other organisations providing community based palliative care. Lastly, recommendations for future research will be presented.

5.2 Conclusions

The following conclusions can be made from the findings of this study.

5.2.1 The positive aspects that palliative care nurses experience in their work

The findings in this study reveal that there are many positive aspects of working in palliative care, which fosters an overall sense of satisfaction and fulfilment, resulting in nurses feeling that their work is meaningful and valuable. The core positive aspects of the participants' work that lead to feelings of satisfaction and fulfilment are patient and family contact, personal gain and working in a team.

The role of the family in palliative care is evident in that the first core positive aspect of working in palliative care is patient and family contact. The three components of patient and family contact that are positive, indicate how significant the journey of working with cancer patients is in that the findings indicate very deep feelings and connections between the nurses and patients and their families.

One can also conclude that the participants found it very rewarding when they can see that the positive results of their intervention in the physical, emotional or spiritual wellbeing of their patients. The literature identifies that making a difference leads to feelings of being hopeful, which creates a fuller understanding of why making a difference is experienced as positive.

Acknowledgement and appreciation is a recurring theme found in the literature and the final component of patient and family contact which was perceived as positive is that participants

feel that their work is recognised and rewarded when they receive appreciation and gratitude from patients and families.

The concept of post-traumatic growth is also evident in this study in that the second core positive aspect of working in palliative care, as identified in this study, is personal gain. The findings indicate that the participants found two forms of personal gain in their work which demonstrated once again that the work that the participants do does contribute to their overall lives. The first was that life lessons learnt which include changing their behaviour and ways of being in their relationships and their response to conflict, strengthening of their faith and spirituality, and a greater appreciation of life due to the awareness of their own mortality and vulnerability.

Personal gain extended beyond the individual to the community and this was evident in that participants were clear that the knowledge and skills gained from their work resulted in them gaining respect in their communities. Furthermore, they feel that they can share their knowledge and their skills as a way of giving back to their communities

The final core positive aspect of working in palliative care is working in a team. Participants felt that team work enabled them to share the workload, and learn and receive support from their colleagues. Working in a team is compulsory in the palliative care approach, and although there were limited participants who identified that when there is conflict or poor communication, working in a team could be challenging, there is an overall sense of satisfaction with regards to working in a team. This is demonstrated further when discussing coping mechanisms used by participants in this study.

5.2.2 The challenges that palliative care nurses experience in their work.

It is evident that working in the field also comes with an array of challenges despite the overwhelming positive rewards of the work. These challenges include the emotional burden of the work, negative personal impact of the work, organisational challenges, as well as difficulties of working in the community.

The emotional burden of working in palliative care pertains to a few factors. The first is persistent rumination about work, which is particularly challenging as it means that even after

working hours, nurses are found to be thinking about their patients and trying to solve their problems in their personal time. The reasons for this include the bond between nurses and the patients or family, or feelings that they are the only people that patients and families can rely on.

Working in this field appears to potentially lead to very complex and difficult feelings and the second challenge pertaining to the emotional burden of the work involves feelings of helplessness. The participants experience anxiety due to feelings of helplessness because of a lack of control over the dying process, resistance from patients or families, and the socio-economic challenges of some communities in South Africa which decrease the comfort and quality of life of their patients.

As much as working with families was seen to be positive, it also was a challenge. The final emotional burden of the work, as identified by the participants is challenging families. Participants feel that they are expected to provide support and guidance to overwhelmed family members, but often find that families are in denial and demanding, with unrealistic expectations of what participants can do.

The work also evidently can lead to negative personal concerns such as physical and chronic health problems, disturbed sleeping patterns, eating habits. Furthermore, participants were also affected emotionally with the resultant inability to be emotionally present with their families due to exhaustion at the end of their work days.

The third core challenge identified in this study is organisational challenges which participants also linked to impacting on patient care. There were two main organisational challenges identified by participants, the first being a demanding workload e.g. high patient loads and administration load. The importance of the role of support from management in organizations was underscored and in this study as the second organisational challenge identified was a lack of support from management and those in leadership positions. Participants feel that their organisations are doing little or nothing to support them in providing care to their patients. Furthermore, they feel that when support is provided, it is not useful or appropriate as it does not meet their needs. Although this study was conducted in two different organisations, it was found that the above challenges were consistent in both organisations.

Once again, the context in which work occurs and how this can influence work was evident because the final core challenge experienced by the participants is the environmental challenges that are a result of working in the community. These environmental challenges included safety issues and driving to patients. The findings of this study conclude that safety was one the most significant challenges identified by the participants as many South African communities have high crime rates. Feelings of anxiety are experienced when needing to go into the community and many participants feel that they often experience an internal conflict as to whether they should prioritise their own personal safety or their patients' wellbeing. As discussed later in the recommendations made by the participants, there is a call for a better understanding of their work, however it is evident that the participants want the challenge of safety to be understood more than any other aspects, demonstrating the significance of this challenge. In terms of driving to patients, participants feel that this is another challenge unique to community based work, whereby they found traffic and working in a large geographical area was added to their exhaustion at the end of their days and affected their ability to get to patients quickly in urgent situations, thus impacting the quality of their care.

5.2.3 The coping strategies that are used to cope with their work.

As discussed, working in this field is accompanied by many challenges and the use of coping strategies assist nurses to mitigate the negative effects of their work. Three personal strategies, which are strategies that have been created by the participants themselves have been identified. Based on the findings, and the literature it could be argued that personal coping strategies have been created by participants in response to the difficulties in their work, as well as the limitations in organisational support. These were the use of family and friends for support, avoidance coping through engagement in activities that assist them to stop thinking about their work and self-care in the form of exercise and taking time out.

Although some participants indicated that they felt that organisational support was limited or not always useful, the use of available support through their organisations was another coping strategy used by some participants. Group support and debriefing was identified as helpful by approximately half of the participants as it creates a space for them to share difficulties pertaining to their work, feel less isolated in their challenges and receive support. However, contrasting to this, some participants did not find a group setting to be useful at all, thus

demonstrating that coping strategies depends on personal preference, and that a one size fits all approach is not helpful in supporting nurses in this field.

Furthermore, the use of colleagues for informal debriefing and support is another organisational coping strategy. Although it may be considered an informal form of organisational support, this in combination with the finding that working in a team is a positive aspect of participants' work, it could be argued that the team approach in palliative care serves as a protective factor for nurses working in the field as it helps them to cope better with their work through sharing the burden, and learning from each other through support and guidance regarding cases.

5.2.4 The recommendations that nurses make to their organisation to improve their working experience

The recommendations made by the participants in this study were in response to and informed by the challenging aspects of their work. Many participants in this study revealed that they perceived that there was limited organisational support and the first recommendation for a one-on-one open door policy for advice and debriefing was made in response to this. The purpose of this policy would be to ensure that those in management are available telephonically or in person, when staff members are needing the support in the moment. The suggestions for the kind of support includes immediate case guidance and supervision and a space to debrief after difficult visits. Despite group support being made available to participants as a form of support, the findings of this study found that it was only useful to some participants and that most participants feel that their recommended method of support would be more useful.

The need for ongoing training and professional development is highlighted in the second recommendation made by participants in this study. A lack of education and training is identified as a significant challenge in the literature, and although a lack of training and skills was not identified as a challenge by most of the participants in this study, the literature as well as participants in this study make recommendations for further training and education that are relevant and consistent within their field were made so that they feel more skilled and equipped in providing palliative care to their patients and family members.

It is important to note that at the time of the study, one of the organisations was undergoing significant change which may have lead participants to make treatment and interaction with staff the focus of the third recommendation. The request for improved interaction with staff was made, specifically pertaining to listening and consultation in a manner that is respectful and trusting. The study identified that participants think that they will feel supported by their organisations if they can be consulted and provide more input into decisions that impact them directly. This finding could be considered valuable in terms of organisational change, which ultimately contributes to their overall experiences of the work, and provides insight into how staff members want to be engaged with during a time of significant change or transition.

Acknowledgement and reward is an issue that is raised a number of times in the discussion of the findings and informs the fourth recommendation which is a request for further appreciation and valuing of staff. As it is a recurring theme, it appears to be an important factor of working in the field that contributes to feelings of satisfaction and therefore should be recognised as imperative. Specific suggestions made by participants include acknowledging top performers for the week, rewarding staff with time off, such as a day or half-day off, to say thank you, and providing a private, comfortable working space. Furthermore, salary reviews were another recommendation to assist staff to feel more valued, but also to retain staff thus creating less stress overall.

The fifth and most common recommendation made to the participants' organisations once again reinforces the importance of the supportive role of management and the need for an understanding of the unique contextual challenges, especially in South Africa, that those working in this field are faced with. Participants recommended that management and those in leadership positions gain a better understanding of what community based palliative care entails as many participants felt that their organisations did not fully understand the conditions of their work. It is suggested that management come to do regular visits with the nurses in the community. Participants feel that this will allow management to have direct contact and exposure to the work that community nurses are doing, and receive insight into some of the environmental challenges as identified in the study.

5.3 Recommendations

5.3.1 The researcher's recommendations for St Luke's Combined Hospices and Tygerberg Hospice

The first recommendation is the provision of emotional support staff in different formats so that all individual needs are met. While some participants expressed that group support and debriefing was helpful, this did not seem to meet all needs. Further emotional support such as individual debriefing and counselling could be provided alongside group support and debriefing so that the nurses feel comfortable and have a choice about the support they want to access. Furthermore, it may be helpful if this is provided by someone that staff can trust, or external people who are not affiliated with the organisation so that the space feels safe. The researcher is aware that there are financial implications to this, however in the long run this may lead to less burn out and compassion fatigue which could save the organisation money paid for sick leave or locum cover. It may also be helpful to explore voluntary support options as well.

The second recommendation is consistent monthly supervision for community nurses. However, alongside this, the researcher thinks that designating people in the organisation who are available immediately in an open-door policy manner may also be helpful for community nurses. This could be offered by the community manager in the organisation, or could be delegated to community nurses who are in more senior positions and are interested in the professional development of their colleagues.

It is imperative to consider the training and educational needs of nursing staff and the researcher recommends that a consistent and comprehensive training programme, that is relevant to the nurses' needs, is provided. If the training budget is limited, it may be helpful to invite external knowledgeable people in the various fields to provide training in the form of in-service training, and in return, share palliative care knowledge with them.

The fourth recommendation considers staff reward and recognition, the researcher recommends that nurses are regularly thanked and recognised for the work that they are doing. This could be done by monthly verbal communication in meetings, or letters of acknowledgement that are given to nurses every six months. Furthermore, highlighting performers of the month based on feedback received by patients and families and rewarding

them with vouchers, breakfasts or other tokens may help staff to feel more appreciated. The researcher is aware that this may have a financial implication, however, in the long run, if staff feel more appreciated they are more motivated and productive, thus possibly resulting in a more efficient service which could attract funders or increased donations.

Finally, the researcher recommends that management does quarterly visits to each community hospice and shadows the nurses for a morning for them to gain optimal and direct insight into what is happening in the community, particularly pertaining to the safety challenges which impacts many of the participants negatively. The researcher is aware that quarterly visits may be time consuming and that management may have other commitments, and therefore recommends that it forms part of the job description of management and that a roster system is created ahead of time to accommodate for this. This action could prove valuable to the organisation as the knowledge gained in these quarterly visits could assist management when creating support structures which could ultimately reduce burnout and compassion fatigue for community-based nurses.

5.3.2 The researcher's recommendations for other organisations providing community-based palliative care

The researcher has identified three recommendations based on the findings of this research and recommendations made by the participants, that could be made to other organisations providing community-based palliative care. The first recommendation considers support structures for nurses, and it is recommended that a range of emotional support such as individual and group is made available to all nurses. This support should be regular and consistent, but an open-door system whereby immediate support is also available should be motivated to be included in the budget. If there is a limited budget, the use of more experienced professionals in the field who are interested in providing support to their colleagues could be considered. A range of support will allow nurses to feel that support is available for their individual needs, and therefore will assist nurses more appropriately in dealing with the difficulties in their work.

The second recommendation speaks to how organisations can contribute to staff feeling that they are appreciated. Due to the difficult nature of providing palliative care in the community, as identified in the findings, consistent staff reward and recognition by management through the means of verbal communication of thanks in monthly meetings and small tokens such as

cards and gifts is recommended to organisations in the field. Feelings of being appreciated and valued regularly may increase the overall motivation of nurses, thus resulting in better productivity overall.

The final recommendation speaks to the importance of organisations to have ongoing debates and discussions of what it means to work in the community. This could be done by regular visits to communities by management, quarterly planning meetings, etc.

5.3.3 Researcher's recommendations for future research

The findings of this research identified a complex dilemma pertaining to the inner conflict that nurses experience when needing to choose between their own personal safety and their patient's wellbeing. Future research could explore how needing to make this decision affects the emotional and psychological well-being of palliative care nurses in South Africa, and if this affects their ability to do their job.

This study also identified that there are unique challenges that nurses experience when working in the community. The researcher recommends that future research could explore how providing palliative care in the community differs to other healthcare settings, such as Intensive Care Units, hospitals and clinics, and whether working in the community contributes to higher levels of distress and exhaustion or not.

This study focussed on nurses' experiences of their work within the field of palliative care, however, there are a range of professionals working within the inter-disciplinary team, who take on different roles. This study identified that due to their specific role, nurses have unique needs. A comparative study could explore how the positive aspects, challenges, coping mechanisms and needs for support are similar and/or different amongst other professionals involved in palliative care.

The final recommendation for research considers the sample of this study, which was relatively small and consisted of only females. It would be important to conduct future research with a bigger sample that could be more representative, and with male nurses as a comparison to see if their experiences would be similar or different to those of female nurses. Furthermore, this study was conducted with nurses working in urban areas, and further research could be

conducted in rural areas to explore whether experiences would be similar or different for nurses providing palliative care within rural areas in South Africa.

5.4 Conclusion

This study sought to examine community-based nurses' experiences of their work, and found that while providing palliative care gave participants a great sense of satisfaction, challenges continue to exist, especially pertaining to being based in the community. The final chapter has presented the main conclusions from the research. The recommendations to the relevant organisations providing community based palliative care have been discussed, and suggestions for future research have been highlighted. Recommendations made by the researcher in this study were made considering the challenges as identified by participants with the intention to guide organisations to support nursing staff appropriately. It is evident that while the findings are consistent with the literature, there is still room for future research in palliative care, and that this is in fact vital as palliative care remains relevant in South Africa due to high rates of end-stage cancer.

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APPENDICES

APPENDIX A: CONSENT TO PARTICIPATE IN RESEARCH

CONSENT TO PARTICIPATE IN RESEARCH

Title of research : Working in Palliative Care: exploring community nurses' project experiences of their work

Researcher : Rachel Williams

Research supervisor : Fatima Williams

Department : University of Cape Town – Social Development

Qualification : MSocSci Clinical Social Work

You have been selected as a possible participant in this study because you are a community nurse providing palliative care to patients at home on behalf of St Luke's Combined Hospices.

1. Purpose and benefits of the study

The purpose of the research is to explore the perceptions that you have about your work as a nurse providing palliative care on behalf of St Luke's Combined Hospices. This includes the challenges, the positive aspects, your coping strategies and your recommendations for support that you feel your organisation could provide to assist you in managing with the demands of your work. It is intended that the findings of the research will be valuable to St Luke's Combined Hospices and that they will respond to the recommendations of the nurses to improve their working experience, although this is not guaranteed.

2. Procedures

Should you volunteer to participate in this study, we would request the following from you:

- Participation in a face-to-face interview that will take approximately sixty minutes. The interview will be set up for between the end of June and the month of July 2018 and will be conducted by Rachel Williams, the researcher.
- The interviews will be voice recorded and transcribed and you will have the opportunity to verify and where necessary amend the transcription.

3. Potential risks and discomforts

It is not expected that the study will bring any physical or psychological risk to you as one of the participants. There is no right or wrong answer to the questions. Your honest view and opinion is all that is needed with regards to your experience. At no point will this information affect you negatively and there will be no direct link between what is said in the interview and your name directly. Should the

interview bring you any psychological stress, a registered counsellor will be available to provide you with debriefing at your request.

4. Confidentiality and protection of participants

Any information that is obtained in connection with this study and that can be identified with you will remain confidential and will be disclosed only with your permission or as required by law. Confidentiality will be maintained by means of removing identifiers such as participant names and assigning codes. A pseudonym will also be assigned to you. All interviews will be recorded and transcribed. All data will be password protected and locked away. Records will be destroyed after a one year period. The findings of this research will be shared with UCT libraries and accessible to other students for research purposes. Furthermore, St Luke's Combined Hospices will receive a presentation of the findings. The findings will also be made available to you in written form.

5. Payment for participation

No participants will receive payment for participation in the study. As researcher I will also not receive any payment for the study.

6. Participation and withdrawal

You can choose whether to be in this study or not. If you volunteer to be in this study, you may withdraw at any time without consequences of any kind. You may also refuse to answer any questions you do not want to answer and still remain in the study. The investigator may withdraw you from this research if circumstances arise which warrant doing so.

7. Contact details

If you have any questions or concerns about the research, please feel free to contact the researcher, Rachel Williams on 072 374 4522 or wllrac004@myuct.ac.za and/or the Supervisor, Fatima Williams on 021 650 3483
or fatima.williams@uct.ac.za.

8. Rights of research subjects

Should you decide to withdraw your consent at any time and discontinue participation, you do this without penalty. You are not waiving any legal claims, rights or remedies because of your participation in this research study.

9. The Researcher

It is important to note that the researcher, Rachel Williams, is an employee at St Luke's Combined Hospices in the capacity of a Community Social Worker. However, in this study, her role is that of a researcher and not employee.

DECLARATION AND SIGNATURE OF RESEARCH SUBJECT

The information above was explained to me by Rachel Williams in clear terms. I was given the opportunity to ask questions and these questions were answered to my satisfaction.

I hereby consent voluntarily to participate in this study. I have been given a copy of this form.

Name of participant: _____

Signature: _____

Date: _____

DECLARATION AND SIGNATURE OF RESEARCHER

I declare that I explained the information provided in this document to _____ [*name of the subject/participant*]. [*He/she*] was encouraged, and given ample time, to ask me any questions.

Signature: _____

Date: _____

APPENDIX B: TRANSCRIBER'S CONFIDENTIALITY FORM

Confidentiality Agreement for use with Transcription Services

Research Study Title: Working in Palliative Care: exploring community nurses' experiences of their work

Student Researchers Name: Rachel Williams

University of Cape Town

1. I, Georgina Selander transcriptionist, agree to maintain full confidentiality of all research data received from the research team related to this research study.
2. I will hold in strictest confidence the identity of any individual that may be revealed during the transcription of interviews or in any associated documents.
3. I will not make copies of any audio-recordings, video-recordings, or other research data, unless specifically requested to do so by the researcher.
4. I will not provide the research data to any third parties without the client's consent.
5. I will store all study-related data in a safe, secure location as long as they are in my possession. All video and audio recordings will be stored in an encrypted format.
6. All data provided or created for purposes of this agreement, including any back-up records, will be returned to the research team or permanently deleted. When I have received confirmation that the transcription work I performed has been satisfactorily completed, any of the research data that remains with me will be returned to the research team or destroyed, pursuant to the instructions of the research team.

Transcriber's name (printed)

Georgina Selander

Transcriber's signature _____

Date _____

12/07/18

APPENDIX C: INTERVIEW SCHEDULE

Research Topic: “Working in Palliative Care: exploring community nurses’ experiences of their work.”

Main Objectives:

- To identify the positive aspects of work that palliative care nurses experience.
- To explore the challenges that palliative care nurses experience in their work.
- To recognise the coping strategies that are used by these nurses to cope with their work.
- To ascertain the recommendations that nurses make to their organisation to improve their working experience.

Phase One: Rapport Building

- Meet and greet, ensuring the participants comfortability
- Thank the participant for participation in the study, remind him/her of confidentiality and voluntary participation
- Clarify the aims and purpose of the interview

Phase Two: Interview

Biographical details

- a) Age
- b) Gender
- c) Marital status
- d) Number of children
- e) What is your nursing ranking?
- f) Number of years as a community nurse at your organisation?

Introductory questions

1. What were you doing before you started working for your organisation?
2. What were your reasons for wanting to work at your organisation?
3. Tell me what your job entails?

Positive aspects

1. What parts of your job do you enjoy (explore areas, i.e. patient care, education, administrative tasks, etc.)?
2. What about these parts/this do you find enjoyable?
3. What is the most fulfilling part of your job?
4. How does your work influence other areas your life positively (explore areas such as personal relationships, family, other interests, etc.)?

Challenging aspects

1. What parts of your job do you find difficult (explore areas, i.e. patient care, education, administrative tasks, etc.)?

2. How do these parts challenge you?
3. What is the most difficult part of your job?
4. How does your work influence other areas of your life negatively (explore areas such as personal relationships, family, other interests, etc.)?

Coping Strategies

1. How do you feel you are coping with the demands your work?
2. How do you manage with the demands of your work?
3. These things that you are doing, in what ways do you feel that they are helpful or not?
4. What do you feel you could do differently or more of?

Recommendations

1. How do you feel your organisation is assisting you in dealing with your work difficulties?
2. How helpful do you find these strategies?
3. If you were your organisation, what would you do to support staff?
4. What recommendations would you make to your organisation to improve your working experiences?

Phase Three: Conclusion and Final Questions

- **Summarise main points of the interview and ask if there is anything else the participant would like to share/add**
- **Explore need for debriefing after the interview**
- **Thank participant for participating and inform them of how the findings will be made available**